

The Experience of Illness and Employment among  
Young Adults  
with a Long-Term Condition

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I declare that the work presented in this thesis  
is my own unless otherwise stated

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**Date:** 15/05/08



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## Abstract

Employment is currently conceived by the UK government as a panacea for achieving social justice among disadvantaged groups in society. Welfare to work policies are being introduced to increase the employment rates of people with ill-health and/or disability. There is little research on how individuals with chronic illness from childhood fare in the labour market as an adult and the perceptions of these groups towards work and career prospects. A qualitative study was undertaken using grounded theory to explore these issues among adults from three disease categories. In total, 30 respondents were interviewed aged between 20-32 years; 10 with cystic fibrosis, 10 with Type 1 diabetes and 10 with arthritis with gender represented equally across the three groups.

Respondents had varying degrees of disease severity. There was, however, a consensus among these young adults in how symptoms were experienced and managed. Respondents viewed themselves as competent individuals and their approach to care reflected this standpoint. Management of illness was largely taken-for-granted and perceived only as intrusive by those with deteriorating health. There was some discrepancy between the apparent advice given by health care professionals and decisions made by individuals about illness which were located in the social fabric of day-to-day activities. No specialist careers guidance had been available to these young adults. Career choice was hindered by lack of educational attainment in some cases and restricted employment opportunities in others. Most respondents were not familiar with welfare to work initiatives. At the point of interview, 20 were in full-time jobs, 2 worked part-time, 3 attended higher educational institutions and 5 were out of work receiving full disability-related benefits. Disclosure of health status in employment emerged as a key issue. Jobs were sought or valued if they were well paid, provided opportunities for advancement and were fulfilling. Half the sample reported having to make some sort of adjustment to manage working lives. The majority of these involved self-care strategies such as buying special adaptations, getting up extra early on work days and making great efforts to accommodate meals into busy schedules. These types of adjustments were seemingly unacknowledged by employers. Few reported direct discrimination in the workplace. Bad employment practice was experienced but this was regarded as poor management behaviour rather than organisational policy. Severity of illness did not appear to be linked to more expressed anxiety about the future. Women in the sample spoke of the tension between lives as desired and lives as experienced in relation to the prospect of having children.

These findings are discussed in relation to past and current research about young people, illness and work and contemporary UK policies on employment and health care.

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## Abbreviations

AHP	Allied Health Professions
CDSMP	Chronic Disease Self-Management Programme
CF	Cystic Fibrosis
D	Diabetes Type 1
DDA	UK Disability Discrimination Act
IB	Incapacity Benefit
ICIDH	International Classification of Impairments, Disabilities and Handicaps
JIA	Juvenile Idiopathic Arthritis
JSA	Job Seeker's Allowance
LMS	Labour Market Survey
NDDP	New Deal for Disabled People
NEET	Not in Employment, Education or Training
NICE	National Institute of Clinical Excellence
NMAHP	Nursing, Midwifery and Allied Health Professions
SEN	Special Educational Needs
UK	United Kingdom
US(A)	United States of America

## **Overview and structure of thesis**

The topic of this thesis, chronic illness and employment, is becoming a major focus of government attention in the UK. The first introductory chapter addresses the legislative framework of policy in this area and sets out the disadvantages faced by those with long-term conditions compared to those without. Chronic illness is increasing in incidence and prevalence and presents a particular challenge to both the NHS and the UK economy. Conditions that begin in childhood have tended to be studied in isolation from larger socio-political processes and this study attempts to address this gap by exploring the social context surrounding the individual.

Chapter two examines the main areas of research undertaken on chronic illness from the perspective of different academic disciplines. Whilst there is a wealth of empirical evidence on the experiences of those with long-term health problems, there is a lack of insider research about the issues associated with employment. The programme of work conducted under the sociology of youth would appear to offer theoretical opportunities to increase an understanding of how young people with child-onset disease fare in the labour market as adults.

In Chapter three, the methodological approach of the research study is provided and the main theoretical concepts influencing interpretation of data are outlined. In order to capture the experiences, feelings and meanings assigned to interactions by respondents, a qualitative study was chosen over a mixed methods design. Grounded theory provided a systematic, inductive approach to data collection and analysis and helped to facilitate theory development.

The process of undertaking the research study is presented in Chapter four. Thirty individuals from three differing disease groups participated in semi-structured



interviews. Data production is an interpretive act which relies to a large degree on the reflexive engagement between the researcher and those interviewed in the study. This section describes how meaning was constructed through the interview encounters and how the various stages of the research were carried out.

Chapters five and six provide the main findings of the study and have been organised around management of illness and management of employment respectively. There were more areas of homogeneity than difference within the sample in terms of how symptoms of illness were experienced and dealt with. Individuals appeared knowledgeable about their conditions and made decisions about treatment within the context of their day-to-day activities. Respondents had different types of employment trajectories depending on health status, age, educational attainment, occupational choices and types of entry into workplaces. Five individuals were not in any form of work, training or education at the point of interview.

In Chapter seven, the theoretical orientation of the research is developed and discussed in further depth. The factors affecting young adults' beliefs and experiences cannot be separated from their social contexts. In this study, respondents acted according to their constructed identities, their personal situations and the opportunities they perceived as available to them. The socio-structural effects of education, employment and family background appeared to be important in understanding some of the differences in outcome for respondents in the study.

The final chapter explores current health care policy and the implications for nursing practice in caring for those with long-term conditions. There is an increasing expectation that nurses will be able to take on an enabling role to promote self-management of illness and health improvement among service users in a variety of health care settings. A framework for rehabilitation has also recently been published

and this document signals a shift in emphasis for health professionals towards recovery and facilitating access to a wider range of service providers. For individuals of working age, employment is seen as a vehicle to aid rehabilitation and the means by which people with long-term conditions can lead productive lives. A critique of this model is proposed in terms of the emphasis placed on the individual to obtain purposeful occupation and the lack of attention given to social and environmental constraints. The imperative to work may also become coercive and this potential must be borne in mind when health care staff are asked to play their part in supporting rehabilitation initiatives for people with long-term conditions.

# CHAPTER 1: CONTEXT, POLICY AND LONG-TERM CHRONIC ILLNESS

## 1.1 Introduction

Chronic disease, once a somewhat 'Cinderella' topic of health care in the UK, is now acquiring a certain cachet in health policy circles. Along with a new image, it is being variously re-branded as a 'limiting long-term illness' (SE, 2004) a 'long-term condition' (DH, 2005; SE, 2005) and 'enduring illness' (SE, 2006a) or assimilated more generally under debates on disability. This recent upsurge in interest has its basis in a combination of factors. The most important drivers in the UK include an ageing population, advances made in medical treatment and management, the accelerated pace of technological and social change as well as policy imperatives to make equal opportunities and equal treatment a reality for everyone.

Alongside a refashioned NHS is the current UK government's commitment to promote social inclusion for excluded youth and those most disadvantaged in society by creating opportunities for them to move from welfare into work. Employment has been conceived of as a panacea for social justice (DWP, 2003; DWP, 2007; PMSU, 2005). Yet, in spite of these key areas for policy reform, the individual experience of managing effects of illness on entering the labour market is severely lacking. For people with chronic illness and their families, social inclusion is both a personal and an increasingly political issue. The effects of impairments at work are not uniformly addressed in the fields of either employment, education or the health service with the result that the disadvantages faced by these groups of people tend to be marginalised or incorporated under discussions of disability.

This thesis is concerned with the comparative experience of those from three disease groups; diabetes, cystic fibrosis and arthritis, from the perspective of young adults who

are at different stages in the employment process. Individuals who become chronically ill from childhood have received relatively little consideration from researchers and not much is known about the perceptions of these people and their attitudes towards work and career prospects. The focus on employment as a principal instrument for inclusion has also yet to be fully evidenced in research terms. In the current scope of public policy in the UK, attention is directed towards excluded youth on the one hand (see (Jones, 2005) and disability on the other (DWP, 2003; PMSU, 2005) which has had the effect of obscuring the needs of people with chronic illness, particularly those of working age.

In encouraging individuals with long-term illness into work, there is a delicate balance to be struck between inducement and coercive practices. There is danger, for example, that welfare to work policies may swing too far in the direction of offering employment incentives. For some people, even those at the beginning of a working life, the prospect of a job may be impossible or difficult to manage because of impairment, the frequency and/or severity of symptoms or simply due to the lack of appropriate job match to skills and type of illness. Within this topic, there are clear areas of debate missing in the current policy literature. These include the lack of understanding and discussion of work issues among front-line staff in the NHS, the extent to which vocational rehabilitation can successfully address the complex social and environmental factors that underlie employment for these groups of people and, perhaps most importantly of all, the premise that employment may be just one of several routes possible to achieve autonomy and social inclusion among those with chronic illness.

This chapter explores some of the language and labels attached to chronic illness and includes a discussion about classification. The prevalence of illness and disability in Scotland is set within a wider UK context and some of the social and economic disadvantages faced by these population groups are described. Employment policy is

enshrined within the UK Disability Discrimination Acts and an appraisal of this legislative framework is outlined. The chapter concludes with an analysis of welfare to work initiatives and information about the three disease-specific areas from which the sample of respondents for the research study has been drawn.

## **1.2 Definition of chronic illness and approach to management in the UK**

In much of the literature perhaps with the exception of disability studies, a definition of chronic illness is seldom supplied. Many authors in the nursing, medical and allied health fields seem to use the term to signify either a specific clinical condition or refer to problems that are common across a range of illnesses. In policy documents, chronic illness is largely classified in relation to disability or ageing although lately this practice has begun to change (see (SE, 2005) as an example). Recent developments in the disability field incorporate illness, impairment and disability within a concept of a social model (Oliver, 1990), a post-modernist approach (Shakespeare and Watson, 2002) or a relational hybrid of the two (Thomas, 1999).

Some commentators (see for example, (Oliver, 1996) have argued that the terms chronic illness and chronic disease are imbued with negative connotations associated with a medicalised approach to illness. In this thesis, however, I deploy these terms in their generic sense with no pejorative intent. As I have found no definitional difference in the literature between 'long-standing illness', 'limiting illness', or 'long-term conditions', I use these terms interchangeably with 'chronic illness' or 'chronic disease' to signify issues relating to a range of persistent illnesses.

From a clinical perspective, various meanings have been provided over the years to classify chronic illness. Eiser and Midence in their reviews refer to long-term disorders as those of at least three months duration but which can last an entire lifetime (Eiser, 1990; Midence, 1994). Wallender and Varni consider that for a condition to be termed

'chronic' it should (a) interfere with daily function for more than 3 months in a year, (b) result in hospital treatment or (c) at the time of diagnosis it should do either (a) or (b) (Wallander and Varni, 1998). Over the last 30 years, there have been increasing calls for a 'non-categorical' approach to the conceptualisation and study of such disorders, particularly those that start in childhood (Martin and Nisa, 1996; Pless and Pinkerton, 1975; Rolland, 1994; Stein and Jessop, 1982). These authors note that there is considerable overlap among paediatric conditions in respect to nature of onset, course, life threat potential, intrusiveness/pain of treatment, visible/invisible effects, stigma and the fact that the burden of care often falls on families.

This broad approach to management is founded on the understanding that children face common life experiences and problems caused by the generic dimensions of their conditions rather than on the characteristics of specific disease entities (Stein and Jessop, 1982). For example, the effect on children of repeated periods of hospitalisation and school absences can be explored regardless of whether admissions have been the result of respiratory disorders, diabetes or joint problems.

More recently, policy-makers and public health researchers have begun to question the concentration of resources on specialist care services for adult populations (SE, 2005; Young and Hayes, 2002). Whilst all agree that disease-specific therapies and individualised treatment plans are necessary, there are service delivery advantages to a non-categorical approach to long-term illness. Integrated and co-ordinated programmes can be targeted to meet the needs of those with a range of diverse conditions, particularly in areas of socio-economic deprivation (SE, 2005). The Kerr Report (SE, 2005) advocates a whole systems approach to management, arguing that traditional boundaries between primary and secondary care may no longer be useful or valid concepts.

From a health perspective, a generic needs approach provides opportunities to focus on holistic care and involve people as partners in decisions made about treatments and management of conditions. It also helps to break down the labelling process of those who are frequently categorised by reference to their diagnosis alone (such as 'diabetic', 'CF' or 'arthritic'). A patient-centred system allows for a more negotiated practice of care that encourages practitioners to perceive and engage with patients as individuals with distinct preferences and experiences. In so doing treatment can be provided in partnership, with support being offered that capitalises on people's strengths and capacities rather than delivered through 'top-down' dictates and overly prescriptive regimens.

### **1.3 Population definitions of chronic illness and prevalence rates in Scotland**

There are various schemas for defining populations with illness and disability in the UK as well as across Europe more generally. Certain European Member States including Britain draw on the model developed by the WHO in 1980 which led to the adoption of the International Classification of Impairments, Disabilities and Handicaps (ICIDH). This framework, now in revised form and called the International Classification of Functioning, has been widely rejected by those in the UK disability movement because of the emphasis in the model on limitations in functional ability as determined by clinical conditions. They maintain (see, (Barnes, 1991; Oliver, 1990; Thomas, 1999) that this has led to a focus on individual shortcomings which has disregarded how aspects of the environment and social structures perpetuate the limitations arising from bodily and/or psychological impairment. Disability from this perspective is perceived as a social construct caused primarily by a society that takes little or no account of people that fall outside the mainstream of the dominant group.

In place of the ICIDH, disabled activists have defined disability in two ways; as 'impairment' which is described as functional limitation within the individual by having a defective limb, organ or mechanism of the body and 'disability' which is the loss or constraints of opportunities to take part in normal life on an equal level with others due to physical and social barriers (Oliver, 1996). As Wendell pointed out, however, national surveys are undertaken primarily to determine patterns of welfare provision in any given bureaucracy so definitions of disability and chronic illness in such studies will always be those that fit the particular social meanings, statutes and roles as measured by people's legal and practical entitlement to forms of assistance (Wendell, 1996).

As well as debates over how to define populations of people with illness or disability (the concepts of which tend to be conflated in official statistics), there are variations with respect to the wording of surveys both between and within different countries. The term 'chronic' may be interpreted to mean either a few weeks, six months, or longer than a year with the result that there can be substantial differences across locations. Including short-term limitations, for example, has been shown to increase disability rates sharply in census populations (Grammenos, 2003). Another important distinction is the evaluation of what is meant by 'severe' and 'moderate' linked to the degree of disability experienced. Again, without precise criteria, this term is very sensitive to variations in reporting. In many countries there has been a drive to include individuals' perceptions of illness in panel surveys although subjective measures may not be directly comparable across nations and could be dependent on specific social issues such as employment status, level of income, receipt of social security etc (Grammenos, 2003).

There are no absolute data on the prevalence of a chronically ill population in the UK as a group distinct from estimates of the number of disabled people and this is further



complicated by the lack of consensus over common definitions. In addition, there has been less focus on disability in Scotland despite the fact that Scotland differs politically, geographically, economically and socially from the rest of the UK (Riddell and Banks, 2001). The establishment of the Scottish Parliament in 1998 underlined the importance of disaggregating data gathered from different parts of Britain in order to chart the growing policy divergence which is emerging (Salisbury and Riddell, 2000). Under the terms of the Scotland Act 1998, responsibility for health, education, training and economic development are devolved matters to the Scottish Parliament whereas employment law, social security and the fiscal, economic and monetary system remain the responsibility of the UK government. In practice, there are often overlaps between reserved and devolved issues, however they are implemented within separate social and economic structures and this factor needs to be taken into account when considering the data sources on the employment position for these groups of people (Riddell and Banks, 2001).

In 2004, a document published by the Scottish Executive entitled 'Social Focus on Disability' was only the fourth official report in Scotland that had collated statistics on Scottish disabled populations in a single, comprehensive format. This publication drew on material from a wide range of sources including the Scottish Household Survey, the Labour Force Survey and the 2001 census. The definition of disability employed in this document was one used previously by the UK government in its implementation of the Disability Discrimination Act of 1995 (see later section in this chapter). This document revealed that in 2002 just less than one in five adults in Scotland had a disability and/or a long-term illness (18% men, 19% women). Older adults were significantly more likely to be disabled than those in younger age-groups: 45% of adults aged 75 and over compared with 9% of those aged between 16 and 34 years (2002 data). The proportion of adults aged between 16 and 64 with a limiting long-term illness was largest within

the White Scottish ethnic group (86.5%) than among those from Pakistani (0.6%) Indian (0.3%) or African (0.1%) backgrounds.

This report (SE, 2004) also provided some Scottish statistics on educational attainment among those with special educational needs (SEN). Data on disabled pupils only started to be collected in Scotland from 2005 so the use of SEN information represents a surrogate measure of disability and is unlikely to include all children with long-term health problems. The results showed that in January 2004, 5% of pre-school children had recognised special educational needs and in September 2003, there were 13, 582 children in publicly funded Scottish primary schools who had a record of need and/or required an individualised educational programme because of health status. Four per cent of students in 2001/2 attending Higher Education Institutions and Further Education Colleges in Scotland had a declared disability.

The Scottish Household Survey (SE, 2004) collects information on the highest level of qualification achieved by adult respondents. Results from 2001/2002 revealed that there were large differences between educational qualifications achieved by disabled people and those with long-term illness compared with the rest of the population (see Table 1).

**Table 1: Highest level of educational qualifications obtained by percentage of Scottish adult population in 2001/2002**

	No qualifications or qualifications outwith those listed	Group 1	Group 2	Group 3	Group 4	Number of people responding in survey
<b>Disability (with or without a long-term illness)</b>	58	13	16	5	9	1, 673
<b>Long-term illness only</b>	54	13	15	7	10	1, 265
<b>No disability or long-term illness</b>	24	19	24	9	24	17, 192
<b>All people aged 17-64 years</b>	28	18	23	9	22	20, 130

*Source: Adapted from Social Focus on Disability (SE, 2004)*

The qualifications within each group are:

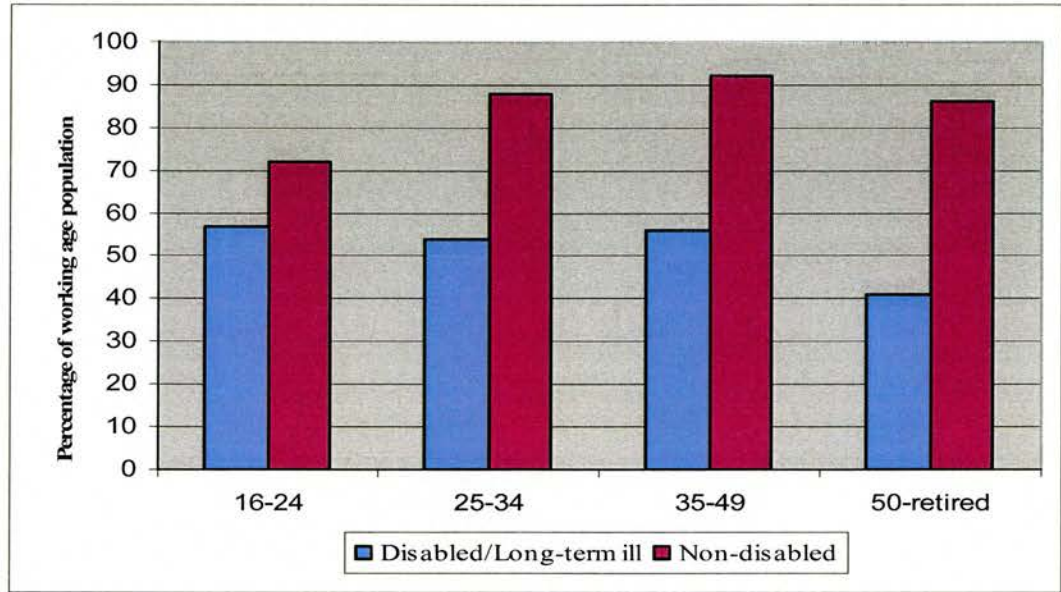
- **Group 1:** 'O' Grade, Standard Grade, Intermediate 1, Intermediate 2, City and Guilds Craft, SVQ Level 1 or 2 or equivalent.
- **Group 2:** 'A' Levels, Higher Grade, CSYS, ONC, OND, City and Guilds Advanced Craft, RSA Advanced Diploma, SVQ Level 3 or equivalent.
- **Group 3:** HND, HNC, RSA Higher Diploma, SVQ Level 4 or 5 or equivalent.
- **Group 4:** First Degree, Higher Degree, Professional Qualification.

Table 1 highlights that the difference in achievement was most marked in the proportion of people who were educated to degree level or above (Group 4). Twenty four per cent of able-bodied adults in this survey reported having a degree compared with 9% with a disability and 10% with a long-term health problem.

Scottish labour market figures (SE, 2004) for those defined as economically active or inactive show a similarly dismal picture between these groups of people. Disabled people form a significant part of the working age population in Scotland. According to the 2003 Labour Force Survey, 662, 000 people of working age in Scotland were estimated to have a disability (which is about 21% of the working age population). Just

under half of these (49%) were active in the labour market (SE, 2004). This compares with a rate of 86% of those without a disability. Economic activity rates for all population groups varied considerably with age (see Figure 1). Figure 1 shows that for the non-disabled population, economic activity was lowest in 2003 at 72% between the ages of 16-24 (due in part to participation in higher education) and increased to 93% for those aged 35-49% and then dropped off slightly at 86% for those aged 50 years on to retirement. By contrast, the employment rate for disabled people was broadly similar for those aged 16-24, 25-34 and 35-50 years at about 55%. The rate then decreased to 41% for those aged 50 on to retirement.

**Figure 1: Economic activity rate for disabled and non-disabled populations by percentage and age-group in 2003**



*Source: Adapted from Social Focus on Disability, SE, 2004*

A more detailed picture of economic activity among people living in Scotland can be gleaned from the 2001 census reports (Riddell et al., 2005). These show that whilst levels of employment were lower amongst both males and females with long-term illness, there were also marked gender differences between part- and full-time working

and in the types of work undertaken within the disability category itself. There were only 3.5% of men with long-term illness who worked part-time compared to 23.8% of economically active women. Table 2 presents data relating to social grade, age and sex for those with and without illness for the age-groups 16-36 and 35-49 (SE, 2005).

**Table 2: Approximated type of work by percentage of age-group and gender of Scottish population in 2001**

Approximated social grade	Non-disabled aged 16-34		Non-disabled aged 35-49		Long-term illness aged 16-34		Long-term illness aged 35-49	
	M	F	M	F	M	F	M	F
<b>Professional</b>	0.7	0.4	2.0	0.6	0.2	0.1	0.4	0.1
<b>Middle manager</b>	14.3	11.6	25.5	18.0	6.1	5.9	10.4	9.4
<b>Other non-manual</b>	26.2	36.1	25.9	38.9	16.9	20.8	16.0	18.5
<b>Skilled manual</b>	22.4	5.2	24.6	5.9	15.4	3.5	17.6	3.5
<b>Semi-skilled/unskilled</b>	24.6	30.2	18.2	27.1	22.7	26.6	17.0	22.7
<b>On benefit/unemployed</b>	11.8	16.4	3.9	10.0	38.8	43.0	38.7	45.7

Source: Adapted from *Disability and Employment in Scotland: a review of the evidence base*, Riddell et al. 2005 (M= Males; F= Females)

It can be seen (Table 2) from these age-groups that a higher proportion of those with long-term illness were employed in semi-skilled and unskilled manual occupations. Among those with illness, females were much less likely to be employed in skilled manual work than males and a higher proportion were on benefit or were unemployed.

The Labour Market Survey (LMS) in 2003 also classified the main type of disability reported by respondents and compared these health problems and their employment rates with others in the dataset (SE, 2004). These sub-analyses showed that 71% of people of working age who listed diabetes as their main illness were economically active compared with 69% of those with chest and breathing problems, 49% of those with problems related to legs and feet and 46% of those with problems with arms and hands. These statistics did not permit differentiation between time of onset of disability

or separation of insulin-dependent diabetes (Type 1) from non insulin-dependent diabetes (Type 2) nor did they cover the specific conditions of arthritis and cystic fibrosis. Nevertheless, these data do provide some broad comparative information at a population level to help put employment rates across Scotland in context.

According to the LMS in 2003 (SE, 2004), full-time working was more prevalent among the non-disabled population as a whole (76% compared to 71% of disabled people in work). Average gross pay for a working disabled person was about 0.9 of that for his/her non-disabled counterpart. The greatest disparity between groups, however, was seen in the income and financial circumstances of households. Data from the Scottish Household Survey in 2001/2 showed that a much higher proportion of households containing disabled or chronically ill members had annual net incomes of £10, 000 or less than households with no disabled or sick person across most household types (for example, 71% of households with at least one member with a long-term health condition had this lower net income compared to 37% of non-disabled households). Furthermore, around a quarter of all individuals living in households with at least one disabled adult were living on considerably low incomes compared to a fifth of those in households with no disabled or sick adult member. Disabled people or those with a long-term illness were also less likely to have investments or savings (SE, 2004).

In August 2003, 554, 000 people of working age (or 18% of the working population of Scotland) claimed at least one key benefit, 65% of which were from those in the sick or disabled groups (Riddell et al., 2005). Within Scotland, there were regional variations with Glasgow, North Lanarkshire and Inverclyde reporting the highest proportion receiving disability-related benefits (9%, 9% and 8% of the total population respectively) and Orkney, the lowest (at 2%). The City of Edinburgh had a relatively favourable position compared to others with 4% of the population in receipt of disability benefits (Riddell et al., 2005).



Placing Scottish data within a wider context of the UK reveals a disproportionate patterning in prevalence and distribution of disabled people living in Scotland than in either England or Wales. About 20% of adults aged between 16-74 in 2001 had a limiting long term-illness across Scotland as a whole compared with 17.5% in England and Wales. Combining data for England and Wales, however, means that regional variations between and within these countries are masked but what is emerging is that there are pockets of acute social deprivation and economic inactivity among those with chronic illness in locations throughout Britain particularly in areas of industrial decline (Riddell et al, 2005).

#### **1.4 Comparative management of employment issues among populations of chronic illness**

From an international perspective, policies promoting social inclusion of people with a chronic illness or disability are receiving increasing attention especially with respect to integration into working life. In Western countries, the trend had been towards enactment of legal constraints to prevent employers from discriminating against workers who have an impairment provided they can still perform the essential tasks of the job. The US, for example, brought in The Americans with Disabilities Act in 1990, the Australian's Commonwealth Disability Discrimination Act came into force in 1992, Ireland introduced its anti-discrimination legislation in 1998 and Sweden's Anti-discrimination Act was implemented in 1999.

In all industrialised societies there have been growing concerns over the number of workers leaving the labour market as a result of illness and becoming long-term claimants of disability benefits (Drake, 2000; van Oorschot and Hvinden, 2000). Governments see their levels of expenditure on social security as excessive and have sought various means of making eligibility rules stricter alongside instigating measures

to promote take up of employment among disabled people (Drake, 2000; Floyd and Curtis, 2000; van Oorschot and Hvinden, 2000). In addition, there are international debates about the best way of reducing the number of claimants and the balance to be struck between encouraging work at the same time as making disability-related benefits less accessible.

Whilst there are significant parallel developments within disability policy being launched across Europe and America, there are still large differences in benefit systems and how services operate between nations and these variations are predicted to remain for the foreseeable future (van Oorschot and Hvinden, 2000). The economic health of any given country appears to determine the levels of employment among ill and disabled populations. For example, higher rates of employment tend to be found in those countries where overall employment is high (Grammenos, 2003). This finding would seem to indicate that societal conditions predominate over any specific factors linked to particular types of illnesses or disability. It seems then that context is all important when examining employment issues among these different population groups. For this reason, a review of the wider social policy background and definition and scope of the Disability Discrimination Act will be confined, in this thesis, to the UK alone.

## **1.5 UK Disability Discrimination Acts**

The first Disability Discrimination Act (DDA) was passed into UK law in 1995 and implemented in December 1996. Various amendments to the Act have been made since and current legislation with regard to disabled people in connection with employment, the provision of goods, facilities and services and the disposal or management of premises is covered by the Disability Discrimination Act of 2005 (implemented on 5 December 2005). There is also a duty placed on all public bodies to promote equality of opportunity for disabled people as an integral part of policy-making, practice and



procedures (implemented in December 2006). These Acts have been modelled on, and have a lot in common with, the Sex Discrimination Act 1975 and the Race Relations Act 1976 and replace early legislation of 1944 (Disabled Person (Employment) Act) which had sought to ensure a fair share in labour force participation of disabled people through a quota scheme and a Register of Disabled People.

For employment purposes, the Act (2005) makes it unlawful for all employers to discriminate against a disabled person, either in considering whether to offer employment or in the treatment of that person when employed, including the taking of decisions about whether to retain or dismiss them at a future time. Amendments made to the Act in 2004 have shifted the 'burden of proof' from the disabled person to the employer. In effect, this has meant that the onus is now on the employer to demonstrate that they have not discriminated against a disabled person rather than requiring the individual to prove the point for themselves. Official guidance on the implementation of the Act is contained in a Code of Practice published by the Secretary of State for Work and Pensions, 2006 and is available on the website of the Disability Rights Commission.

#### 1.5.1 Who is disabled and what is discrimination under the Act (2005)?

The DDA protects only those individuals who are disabled within the meaning of section 1 of the Act. The Act (2005) provides that a person has a disability if he/she has a physical or mental impairment which has a substantial and long-term adverse effect on his/her ability to carry out normal day-to-day activities. Some physical impairments automatically meet the definition of disability contained in the Act (2005) such as those who are registered blind or partially sighted and those with severe disfigurements. People diagnosed with HIV, cancer, and multiple sclerosis are also deemed to be covered by the Act (2005) from the point of diagnosis. For others, the inability to carry out normal day-to-day activities must fall within a prescribed and exhaustive list:

mobility; manual dexterity; physical co-ordination; continence; ability to lift, carry or otherwise move everyday objects; speech, hearing or eyesight; memory or ability to concentrate, learn or understand; perception of the risk of physical danger. Long-term means in effect 12 months; substantial and adverse are defined as 'more than minor or trivial' and 'very unfavourable' respectively and examples provided in the Act (2005) include: difficulty in going up or down stairs or steps, inability to hear and understand another person speaking clearly over the telephone and persistent difficulty in remembering the names of familiar people such as family or friends.

### 1.5.2 Reasonable adjustments

It is judged to be discrimination according to the Act (2005) if an employer treats a disabled person less favourably than he/she would treat others, for a reason which relates to that person's disability unless the employer can show that the treatment is justified. It is also discriminatory if an employer fails to make reasonable adjustments which would overcome any arrangements made by the employer, or any physical feature of the premises, which places the disabled person at a substantial disadvantage. The types of adjustments the Act (2005) has in mind include rearrangements of duties, working hours or place of work, providing training opportunities, allowing absences during working hours for rehabilitation, assessment or treatment and providing a reader or support worker where necessary. Whilst an employer has a positive duty under the Act (2005) to make reasonable adjustments, this duty is not absolute and may take account of extraneous circumstances such as cost, scale and disruption to the existing workforce.

### 1.5.3 Critique of the UK Disability Discrimination Act (2005)

The definition of disability provided in the Act (2005) has been heavily criticised by many disabled organisations for its emphasis on the functional limitations of an individual (a so-called medical model) as opposed to one that sees disability primarily

as an outcome of disabling social arrangements and barriers (for further information see section in the next chapter under Disability studies). It is also unclear precisely which different chronic illnesses and impairments are covered under the Act. Long-term conditions are dynamic as opposed to static in their manifestation; they may be progressive, intermittent or continuous and the ways in which a person with effects of illness interacts with their environment may affect issues around disability and work. The Act (2005) as it currently stands would not necessarily ensure protection for all those with chronic illness who experience discrimination. Notably, it would appear that a person with a progressive condition is unlikely to be covered by this legislation until at least the point at which the impairment actually affects their ability to carry out the normal day-to-day activities as specified by the Act. Even then, it would still be necessary to demonstrate that the effect is longstanding in nature and likely to remain so.

Curtis has also reported that since the implementation of the Act in 1996, over 5,000 complaints against discrimination at work have been filed (Curtis, 2003). The majority of these have been from disabled people who were dismissed from jobs that they had had previously and only comparatively few relate to those who consider they have been discriminated against in recruitment or in other ways. Of the claims already disposed of at tribunal hearings, 23% have been successful and 77% unsuccessful. Representation appears to have been a beneficial influence on outcome since applicants represented by lawyers claim a 30%-40% success rate compared to trade unions, 21.7% successful and those unrepresented, 15.6% successful (Curtis, 2003). The most common reason put forward by employers as justifying discrimination was the employee's state of health or the amount of sick leave taken, cited in 26.4% of cases (Curtis, 2003).

In an article reviewing the recent key disability discrimination judgments to date, Crick highlights how the DDA is evolving subject to precedence set through Court hearings

(Crick, 2006). He maintains that the 2005 amendments to the Act have widened the scope of the legislation and impose a positive obligation on employers to focus less on the precise medical condition of an employee and more on the fairness and reasonableness of how each is treated. However, the low levels of success for disabled people in the law courts are of particular concern given the evidence of negative workplace attitudes towards recruitment generally (Roulstone and Barnes, 2005). Indeed, in one case that was heard, a postman suffering from osteoarthritis and chronic back pain alleged that he had been discriminated against after being dismissed by the Royal Mail Group on grounds of ill health. The employment tribunal turned down the claimant on account that he had not convincingly demonstrated that he was disabled within the meaning defined by the Act. Crick also makes the point that it is not clear whether employers are obliged through the DDA (2005) to extend sick pay in circumstances where disabled employees are off work for disability-related reasons (Crick, 2006). The success or otherwise of the DDA in enhancing the employment position of disabled people and those with chronic illness requires longer-term monitoring. As yet the law is relatively new and is generating many issues for reflection and debate.

## **1.6 The UK welfare to work policies**

Soon after coming to power in 1997, the New Labour government announced a broad programme of welfare reform which included a general policy shift towards encouraging those on long-term Incapacity Benefit (IB) into employment. In making good on their promise to ensure 'Work for those who can, security for those who cannot' (DSS, 1998) the government pledged to introduce a 'windfall tax' on recently privatised utilities and use the £5 billion or so generated to help young people come off welfare and obtain work. The welfare to work initiative was created within which the New Deal for Unemployed People was launched and subsequently a specific scheme for disabled people (New Deal for Disabled People) on a budget of £195 million (Floyd

and Curtis, 2000). A large proportion of the budget was spent on testing out a new 'personal advisor' service. This was piloted in 12 different areas across the UK, with the service provided directly by the then Employment Service (now termed Job Centre Plus) in six cases and by a consortia of organisations in the remaining areas. Evaluation of the schemes carried out so far has found that whilst the New Deal for Young People saw youth unemployment go down by about 30,000 in the first year (although it has been projected that half would have probably found jobs anyway), the take-up rate of the New Deal for Disabled People (NDDP) was relatively low (Corden et al., 2003; Stafford, 2005). The most common reason given by potential clients for not participating in the NDDP scheme was that they were too unwell although, interestingly, some people did not take part as they did not identify themselves as 'disabled' (Stafford, 2005). In general, however, clients who did participate were positive about the programmes and were satisfied with their progression towards employment (Corden et al., 2003; Stafford, 2005). Partnership was an important element in both schemes and the initiative revealed new ways of working with employers and disability bodies and in integrating different aspects of the process into a single pathway. The NDDP became a fully national service in July 2001 with the idea of a personal adviser service being retained. Different parts of the initiative are still being evaluated but some commentators have expressed concern about the target reach of the programme (Corden et al., 2003) and the lack of plans to collect data on impact and longer-term outcomes (Stafford, 2005).

Whatever its shortcomings, however, welfare to work represents a major shift in policy. While mainstream New Deal is targeted at people receiving Job Seeker's Allowance (JSA), that is those regarded as fit for but without work, the disability specific scheme is focused on those in receipt of Incapacity Benefit (IB) or other disability-related benefit, that is those not regarded as capable of work. Previously, help from the Employment Service would normally only have been given to those on JSA or others deemed fit for

employment. As Roulstone and Barnes noted, NDDP embodies an intrinsic paradox for those on IB who seek work as they must simultaneously demonstrate their incapacity for employment in order to be eligible for benefit as well as declare themselves willing to consider job opportunities as they arise (Roulstone and Barnes, 2005). This tension translates into significant risks for disabled people and the long-term sick who wish to undertake either paid or voluntary work as their benefits may be placed in jeopardy. The Government has tried to resolve this anomaly by putting forward a higher earnings disregard threshold which has been largely welcomed but the contradictory requirement that disabled people must be able to prove themselves both fit/unfit for work appears to perpetuate suspicion in both disabled people and in potential employers (Roulstone and Barnes, 2005).

Corden has also argued that being able to work for these groups of people is rarely an 'all-or-nothing' concept (Corden, 2005). Those with fluctuating conditions or recurring symptoms, for example, may be able to do some kinds of work full-time or other kinds at discrete intervals in times of remission. The nature of some people's health condition means that they might prefer working only part of a day or week, resulting in relatively low earnings. Individuals in these circumstances may see particular risks in leaving behind the security of IB (or similar disability-related benefit) entirely, particularly if they have already met the criteria for eligibility. In the last two to three years the government has provided financial incentives to encourage different ways of trying work without loss of benefit but the complex number of tax credits and schemes on offer has made it difficult for some to understand their own position and options available (Corden, 2005). It is also important to record that for most IB recipients, health-related barriers are their main reason for not undertaking paid work (Corden, 2005). As such, welfare to work as the foremost instrument of social inclusion for these groups may operate perversely to further exclude significant numbers of already disadvantaged people.

In addition, there is pan-European evidence that despite different disability policy regimens, the levels of success for disabled people entering sustained employment remain consistently poor (Grammenos, 2003). Any simplistic assumption that all disabled people can work has substantial implications for groups who may experience the greatest barriers in gaining and keeping employment. Roulstone and Barnes (Roulstone and Barnes, 2005), for example, remain critical of the official policy understanding of the resistance to paid work among some disabled people as representing a 'culture of dependency and low expectations' (PMSU, 2005). They suggest alternative explanations such as low employment opportunities in the UK labour market for disabled people and the notion that those who have never worked but would like to receive little attention in policy terms. Millar also makes the point that the New Deal programmes have been most effective at serving people who need a bit of help rather than those who need a lot (Millar, 2000). In particular, welfare to work initiatives need to address those with multiple impairment effects and special needs who are likely to experience the greatest difficulties with barriers to employment and exclusion from social activities.

## **1.7 Background to the research**

My research interest in exploring employment experiences arose from a professional rather than personal source. The study itself evolved during my employment as a Research Nurse on a Respiratory Unit at a teaching hospital in central Edinburgh. I attended a seminar given by a medical student about quality of life issues in people with cystic fibrosis. The topic of working lives was but one small factor in this talk but it stimulated my curiosity sufficiently to explore the subject in more depth. When looking through the literature, I was struck by how little was known about employment issues in adults with cystic fibrosis.



I subsequently undertook searches of work related to other chronic conditions and as a result extended my original concept to compare and contrast experiences of employment among individuals from three different child-onset chronic disorders, those of cystic fibrosis, juvenile idiopathic arthritis and Type 1 diabetes.

At the outset, the research questions I was aiming to gather data on were as follows:

- How do young adults with chronic illness obtain work and maintain working lives?
- What factors facilitate and impede employment opportunities in young adults with chronic illness?
- Are transitions from school/education to work helpful in exploring facilitators and barriers to successful employment?
- What are the wider structural implications of young chronically ill adults' participation in the labour market?

## **1.8 Disease-specific information**

Relatively little research attention has been devoted to understand how those who experience ill-health throughout childhood and adolescence fare in the labour market as an adult. The work undertaken for this thesis attempts to address this gap by focusing on three common, chronic illnesses that affect substantial numbers of people in the UK. Information is provided on these disease-specific areas and their respective patient organisations in order to set the effects of illness and management of condition in context alongside the prospect of working lives. Further detail on the clinical manifestations of these disorders can be obtained from medical textbooks such as Davidson's Principles and Practice of Medicine (Boon et al. 2006).



### 1.8.1 Cystic Fibrosis

Cystic fibrosis (CF) is a complex multi-system disease. It is caused by a faulty gene that controls the movement of salt around the body resulting in secretions that clog vital organs making it difficult to breathe and digest food. More than 7, 5000 people have CF in the UK today and about five babies are born every week in this country with the condition (Dodge et al., 1997). The disease appears to be most prevalent among White populations of European ancestry and whilst common worldwide it is found much less frequently among Black, Hispanic and Asian ethnic groups (NIH, 1990). The severity of symptoms of CF vary markedly but the condition as a whole is characterised by chronic respiratory obstruction, dysfunction of the exocrine glands and pancreatic insufficiency that can lead to poor digestion and poor growth. At present, the average life expectancy is 31 years but this figure refers to treatment regimens that were in place in the 1970s and 1980s and considerable advances in management have been made since then. Indeed, projections of survival estimates have suggested that affected children born in 1990 may have a median life expectancy in the order of 40 years (Elborn et al., 1991). With the prospect of gene therapy to help treat lung problems in the future, others predict a near-normal life length for some of those with CF born today (Walters, 2003).

Self-management forms a key part of an individual's daily life with CF. Most require regular medication in the form of bronchodilator and steroid inhalers and tablets with meals to aid digestion. Regular exercise and physiotherapy are also encouraged to help clear the lungs of mucus which attracts infections. About one in eight people with cystic fibrosis also develops diabetes due to damage and blockage to the pancreas and in these circumstances, daily injections of insulin are also needed (CFTrust, 2004). Complications such as recurrent lung infections and cross-infection are common and require intensive management. There are no National Institute of Clinical Excellence (NICE) guidelines on the management of children or adults with cystic fibrosis.

Examples of good practice are set by specialist services across the UK with protocols endorsed by the British Thoracic Society, the Royal College of General Practitioners, the British Paediatric Respiratory Association and the Cystic Fibrosis Trust (CFTrust, 2001; CFTrust, 2001b; CFTrust, 2004).

The CF Trust is a well-funded, charitable organisation set up in 1964 to raise the profile of cystic fibrosis and to fund medical and scientific research to develop a cure. It also provides information, advice and, where appropriate, financial assistance to anyone with CF and helps ensure effective health care by participating in the development of standard setting. In 2006, the Trust published a fact sheet available from their website on employment specifically to help those with CF obtain and retain a job ([www.cftrust.org.uk](http://www.cftrust.org.uk)). It encourages disclosure of CF in the workplace and provides an explanatory sheet for employers that emphasises their responsibilities under the UK Disability Discrimination Act. The fact sheet also provides areas where adjustments in employment may be made such as in arranging annualised contracts in hours, sick leave allowances and in providing rest rooms and a fridge for the storage of medications.

### 1.8.2 Diabetes

Diabetes is a serious and rapidly growing health problem both in the UK and worldwide. It was predicted that in 2005, about 333 million people aged 20-79 had diabetes across the world (Amos et al., 1997). More than 2 million people in the UK have been diagnosed with the condition and this number is estimated to reach 3 million by 2010 (DiabetesUK, 2006). In Scotland alone, 170,000 people have diabetes and it is believed that thousands more have the disease but are not aware of it (SE, 2006c)

The pathogenesis of diabetes is unclear. Various hypotheses have been put forward to account for the condition but there remains no unifying theory of disease causation

(Daneman, 2006). Some argue that diabetes is a single condition rather than two distinct entities, Type 1 and Type 2 (Wilkin, 2001). For others, there is insufficient evidence to support this hypothesis (Daneman, 2006) and most documents distinguish between each type in terms of clinical management (DiabetesUK, 2004; SE, 2006c).

Insulin is essential for the conversion of glucose into energy. Type 2 diabetes is due to varying combinations of insulin deficiency and insulin resistance and its increase is closely linked to an ageing population and rapidly rising numbers of overweight and obese people. Type 1, on the other hand, mainly occurs in childhood and at a low incidence throughout adulthood and is caused by the lack of insulin as a result of autoimmune destruction of the islet beta cells in the pancreas (Daneman, 2006). An estimated 18,000 people have Type 1 diabetes in Scotland in 2004, about half of whom were diagnosed below the age of 15 (DiabetesUK, 2004). The incidence among children appears to be rising globally as well as in the UK at a rate of between 3% and 4% a year although the reason for this increase is unknown (Collado-Mesa et al., 1999). There are differential prevalence rates of diabetes among populations across the world but Type 1 is most common in Finland and Sardinia and lowest in China and Japan (Daneman, 2006; DiabetesUK, 2004). Migrating populations appear to take on the incidence rates of their new countries so, for example, those of South Asian children in the UK resemble those of White or other ethnic backgrounds in the same area.

Diabetes is associated with serious chronic ill health, disability and premature mortality (DiabetesUK, 2004). Long-term complications include heart disease, stroke, blindness, kidney disease and amputations. However, there is evidence from a variety of studies that consistent control of blood glucose levels prevents or slows down the progression of microvascular (retinopathy, neuropathy) and macrovascular (cardiovascular, cerebrovascular and peripheral vascular disease) problems caused by diabetes (Daneman, 2006; DiabetesUK, 2004). It has also been shown that those initially treated

intensively to achieve good blood sugar concentrations continue to have greater protection against development of complications over time (DCCT/EDIC, 2000; DCCT/EDIC, 2002). Since the discovery of insulin in the 1920s, Type 1 diabetes has been transformed from a disease of certain death to one where effects of illness can be effectively managed and controlled. However, at a population level, the complications caused by diabetes reduce rates of mortality. For example, it has been estimated that a 10 year old boy or girl developing diabetes in the year 2000 might lose, on average, 18.7 and 19.0 life-years respectively compared with non-diabetic peers (Daneman, 2006). Furthermore, advances in treatment for those with Type 1 diabetes have resulted in improved outcomes at the same time as placing complex and expensive therapeutic demands on individuals.

Self-monitoring of blood glucose is fundamental to diabetes care (DiabetesUK, 2004; DiabetesUK, 2006; NICE, 2004; SE, 2006c). Frequent monitoring improves glycaemic control, avoids low blood sugar levels (hypoglycaemia), and facilitates lifestyle flexibility particularly when the results are used by individuals in conjunction with making appropriate choices about diet, physical activity, and doses of insulin (DiabetesUK, 2004; Evans et al., 1999; SE, 2006c). In 2002, The Scottish Executive published a Diabetes Framework which set out a 10-year programme of reform to address the increasing problem of diabetes in Scotland (SE, 2002). Central to this Framework is the monitoring of explicit clinical standards to make clear what level of care patients should expect. The Diabetes Action Plan of 2006 highlighted the requirement for a greater focus on the needs of people with Type 1 diabetes. A key aim of this document is patient-centred care with services being designed to facilitate self-management by ensuring that all people have access to appropriate information and education.

The Scottish Intercollegiate Guidelines Network provides recommendations for effective health care based on current evidence. The document, *Management of Diabetes*, was published in 2001 and supplies specific aspects of good practice along with the strength of supporting evidence (SIGN, 2001). NICE produced its clinical guideline on Type 1 diabetes in July 2004. Both texts emphasise the importance of education, self-care and patient-centred approaches in the management of children and adults with diabetes and advocate the development of programmes designed to empower individuals to make judgements and choices about their own health care.

Diabetes UK is one of Europe's largest patient organisations. Its stated mission is to improve the lives of people with diabetes and to work towards a future through research into better treatments and search for a cure. There is no document on the website that provides advice specifically on employment matters but individuals are encouraged to contact the organisation with queries relating to diabetes. The organisation boasts over 170, 000 members and produces a wide range of magazines, books and leaflets and has a network of offices throughout the UK.

### 1.8.3 Juvenile Idiopathic Arthritis

Juvenile Idiopathic Arthritis is a group of inflammatory disorders of unknown aetiology. It is also variously termed juvenile chronic arthritis, juvenile rheumatoid arthritis, juvenile arthritis or in its extreme form, Still's Disease. The three major subsets of the condition are pauciarticular arthritis, polyarticular or polyarthritis and systemic disease (Foster et al., 2003). The former often starts at the age of two or three and usually affects 4 or fewer large joints such as the knee(s), ankle(s) or wrist(s). Sometimes the eyes are affected too. Polyarthritis can affect five or more joints and may begin at any age and usually spreads from one joint to another quite quickly. Children often feel generally unwell, sometimes with a fever. In the third type, the inflammatory process affects the whole body and causes fever and rashes as well as inflamed and

painful joints and usually presents before age 5. In many cases, chronic inflammation stops in late childhood but about a third of children continue to have problems into their adult life (Foster et al., 2003).

About one in 1000 children in the UK has arthritis (Manners and Bower, 2002). The most common form, pauciarticular-onset, accounts for about 50% of cases and the polyarthritis or polyarticular type occurs in about 20% of children. These forms are found most frequently in girls although both sexes are affected with equal frequency in systemic-onset disease (Manners and Bower, 2002). Few studies document racial differences but it appears that juvenile arthritis is more common amongst White northern European races (Manners and Bower, 2002). The most common features of JIA are joint inflammation, joint contraction (that is stiff, bent joint), joint damage and/or alteration or changes in growth. Presentation, however, can be variable and signs and symptoms can differ from child to child and even from day to day within the same child. Other problems include joint stiffness following rest or decreased activity (hence morning stiffness) and weakness in muscles and other soft tissues around involved joints. Because the disorder affects each child differently, children also vary in the degree to which they are affected by a particular symptom (Foster et al., 2003).

There is no single test to diagnose JIA. Diagnosis is usually made when there has been persistent arthritis in one or more joints for at least 6 weeks after other illnesses have been ruled out. Sometimes, a variety of tests is necessary to reach a firm diagnosis. Management includes regular physiotherapy, hydrotherapy and occupational therapy to maintain function and prevent deformities as well as prescribing regular medication such as non-steroidal anti-inflammatory drugs (for example, ibuprofen, naproxen), analgesics and intra-articular steroid injections directly into affected joints. Disease-modifying anti-rheumatoid drugs are also increasingly being used early in the disease process in children and young adults but these have significant potential toxicity and

require careful monitoring. Methotrexate is now considered the most effective of these agents (Ramanan et al., 2003) although hydroxychloroquine, gold, sulphasalazine and immunosuppressants are also frequently prescribed. Surgery such as joint replacement or synovectomy is also undertaken in severe cases.

The prognosis for those who develop juvenile idiopathic arthritis tends to be favourable overall but morbidity and mortality rates vary substantially depending on type. In about 80% of those with the most common form of arthritis (pauciarticular), symptoms resolve completely after about 15 years (Adib et al., 2005). A subset (approximately 15%) go on to develop polyarticular arthritis and have severe joint involvement. Eye complications can also become a major problem in this group with many developing cataracts and/or glaucoma or presenting with reduced visual acuity at ten years after diagnosis (Adib et al., 2005; Minden, 2006). Those with polyarthritis as a child appear to experience a variable prognostic course. In rheumatoid factor sero-negative cases, only 10-15% continue to have severe limitations at 15 years with the majority going into remission with little erosive disease. By way of contrast, sero-positive individuals, tend to follow a more severe route into illness with about 33% remaining independent after 15 years (Foster et al., 2003). Half of those with systemic onset remit without recurrence but the rest have polyarticular arthritis and 33% have severe joint destruction. Prognosis appears to be worse in those with disease onset before the age of 5 years. About 4% of this group die from infection and amyloidosis (Adib et al., 2005; Minden, 2006).

A recent survey of Scottish NHS Boards undertaken by the National Rheumatoid Arthritis Society estimated that about 81,500 people in Scotland have some form of inflammatory arthritis (NRAS, 2006). The services for this chronic condition, however, appears to vary considerably across Boards in terms of care and management, the extent to which patients and voluntary organisations are involved, the amount of



support provided for self-care and treatment and availability in access to specialist health professionals as a co-ordinated part of service provision. There is currently no strategy for inflammatory arthritis in Scotland in spite of the prevalence and impact of this condition on individuals and their families. Current evidence-based guidelines now recommend more aggressive treatment of arthritis on diagnosis (Luqmani et al., 2006; SIGN, 2004) with the potential to improve outcomes in the long-term.

Self care in arthritis resolves around the management of musculoskeletal pain and fatigue. Child-onset arthritis has a major impact on the growing skeleton with growth and bone mass being markedly reduced by persistent inflammation and corticosteroid use. Educational programmes are developing in rheumatology but these are not static, non-stop packages and require to be delivered at various times during the course of the disease (Luqmani et al., 2006). There are two voluntary organisations within the UK that provide advice and accessible information for people with arthritis, Arthritis Care and the National Rheumatoid Arthritis Association. Arthritic Care produces a leaflet about finding work that refers to the recent welfare to work initiatives and encourages individuals to look for employers who have joined the 'Positive about Disability' scheme.

## **1.9 Conclusion**

Definitions such as disability and long-term illness can no longer be unquestioningly used. Those officially accepted by government bureaucracies determine levels of welfare and have profound consequences for people who do or do not fit the disabled person criteria. There is major concern both within and outwith the UK about the growing numbers claiming incapacity and other disability-related benefits and the low employment rates among disabled people and those with long-term illness. As yet, welfare to work programmes have had only a modest impact on reducing rates of economic inactivity among these populations.



The next chapter explores the literature on chronic illness, young people and employment from a variety of perspectives and disciplinary traditions. It also helps to set the research study undertaken in context amid the proliferation of policy documents and other research published about excluded youth and studies of employment among disabled groups.

## **CHAPTER 2: THE LITERATURE ON CHRONIC ILLNESS AND EMPLOYMENT**

### **2.1 Background to searching the literature**

Reviewing the literature for this thesis was in practice a progressive and iterative activity. Various search strategies were undertaken at key stages during the course of study and when the existence of other literatures in different fields became known. A detailed search for information on employment issues was initially performed on application for entry as a doctoral student (March 2001) although the focus at this time was primarily on the three distinct disease groups. The end of year one necessitated the production of a 5000 word report justifying and describing my proposed research study. Again, there were updated searches of the literature carried out then as well as a review of research methods and other related information.

I had also become aware at this point of the growing body of writing about disability by disabled scholars, activists and other academics although much of the recent work on disabled people's employment had not at that time been published. Indeed, the main sources of evidence referred to in this chapter and in the discussion were not available to me until some time after completion of my data collection. Because of the intense public policy interest in employment and in chronic illness since the start of my thesis, I undertook a third, more rigorous appraisal of the literature in 2006 across various databases. The next section describes this strategy in more detail. A flow-chart of the process has also been included for reference on page 36.

To obtain a comprehensive review of the literature, cited reference searches from various original texts were also conducted. These led me occasionally in unexpected directions; indeed the literature about youth transitions arose as a result of such a tactic but the newer strands of work published by the Joseph Rowntree Foundation were

found through electronic sources. In addition, for about the past five years, I have set up email alerts on my computer which automatically provide me with articles in key journals at the point of publication. These are particularly useful for keeping on top of information about which there is an extensive literature. Hand searching for articles and books in libraries and through electronic journal sites is also an important ploy to adopt when key words have failed to locate all the expected work in the area. I found, for example, that papers in the journal, *Disability and Society*, were rarely cited in the search strategies I carried out using bibliographic databases. It was necessary to deploy all available methods to locate information about chronic illness and employment which appeared to be dispersed across a wide variety of data sources.

## **2.2 Search strategy in June 2006**

There is an immense volume of work on chronic illness. In June 2006, in order to further investigate the scope of published literature in this area, a search was undertaken in Medline which limited reference citations to between the years 1985 to 2006. This approach resulted in 167, 088 citations. When combined with other electronic databases to include nursing, biomedical, psychological and sociological literature (Medline with Cinahl, British Nursing Index, EMBASE, Health Management Information Consortium, PsycINFO, Allied and Complementary Medicine and Social Work Abstracts), an additional 12, 318 references were identified. This number of papers would have been impossible to review.

Restricting the topic headings to 'Chronic Illness' ('Chronic Disease' used in Medline) and 'Employment or Job' for the same time span generated a smaller but still substantial evidence-base: 1, 059 in Medline and an additional 345 from other databases. These numbers were reduced slightly to 1, 373 by limiting the search to articles published between 1988 - 2006 in the English language and by removing duplicate citations. The majority of these references centred mainly on clinical outcomes

or referred to associated but not entirely analogous concepts such as health-related quality of life. In the end, 168 journal articles were identified from which the title and abstract were examined for relevance to aid background information on my areas of interest. It is possible due to the search terms used and my selection strategy that important papers or books have been overlooked. Nevertheless this approach aimed to be inclusive rather than exclusive and used a number of different databases to try to identify all relevant publications.

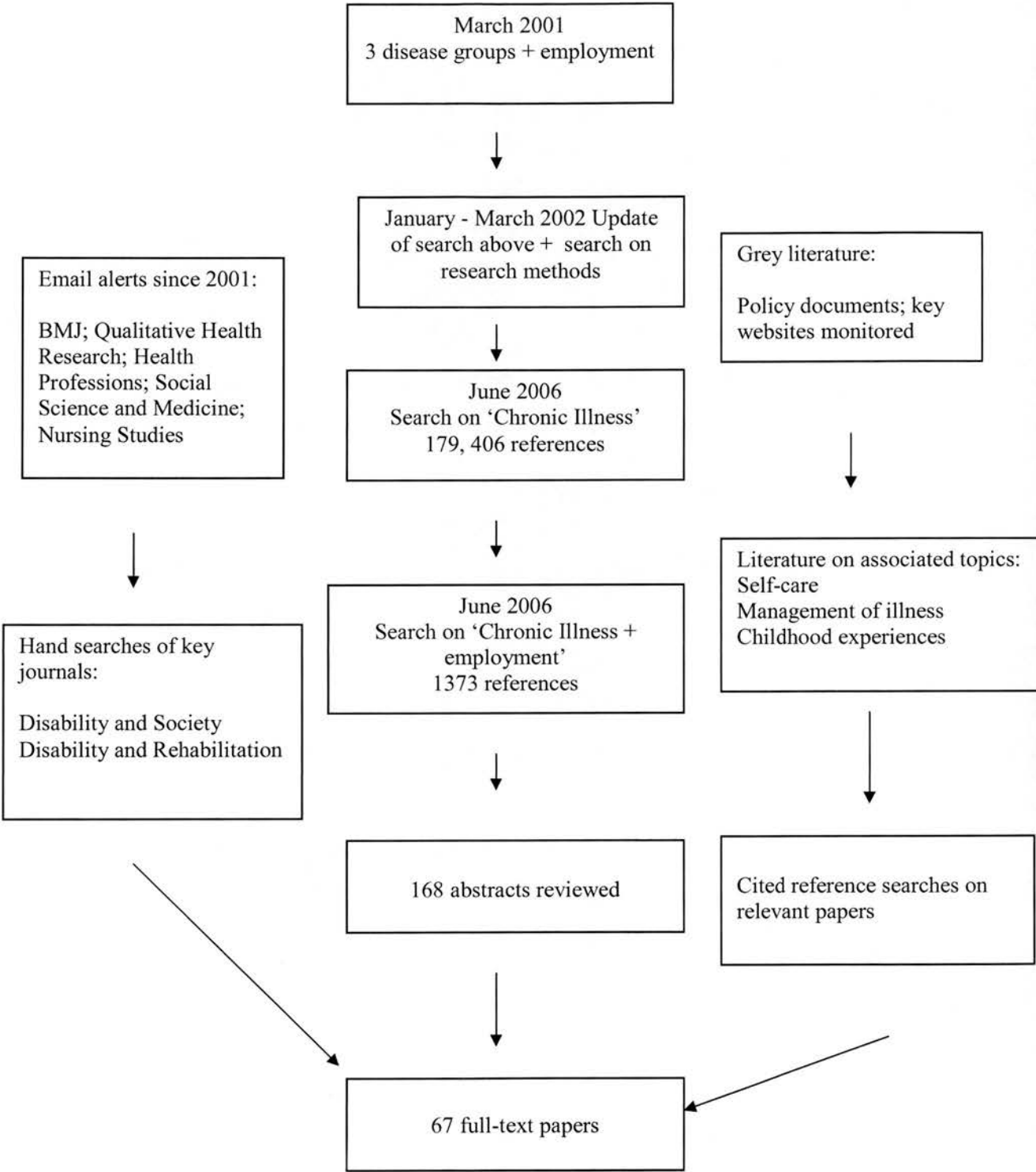
Sixty-seven full-text papers were eventually retrieved for focused review from this strategy. The current resurgence of interest in chronic illness and the wider interdisciplinary scope of work-related issues, however, suggest that there may be a considerable amount of grey literature about this topic (that is unpublished reports, policy documents, briefing papers). To try to access all potentially relevant documents, the publication sections of websites belonging to the National Research Register, the Department of Health, Scottish Executive and other organisations such as the British Society of Rehabilitation Medicine and the Economic and Social Research Council were examined. Additional information was also gathered from the Disability Rights Commission and the King's Fund.

Whilst focusing on employment experiences of adults with chronic illness, a general search was also made for other information of possible importance to the study, such as articles about self-care, disclosure of condition and childhood experiences. Again, there is an extensive literature on each of these issues and a review of published material has had to be selective rather than inclusive in these fields.

The literature on chronic illness and employment and related information is included mainly in this section but some has also been introduced in later Chapters. The major theoretical precepts driving academic debate within disciplines are covered here along

with the principal ideas arising from empirical studies. Where literature links to findings from my own investigation, this has been incorporated into Chapters 5, 6 and 7. Inevitably, there is some overlap. Any new information presented in the discussion, particularly on self-care, is of secondary importance only in terms of the key arguments of this thesis and has been used primarily to augment interpretation of data and main themes.

Figure 2: Search strategy



### **2.3 Conceptualisation of chronic illness**

The literature reveals many ways of approaching and investigating chronic illness. In part, this difference reflects disciplinary debates about how disease, impairment and disability have been and are currently conceived by various academics; from sociologists, psychologists, health professionals and policy makers alike as well as various subsets in-between these groups. What seemed clear on reading texts was how the strands of work within these fields rarely converged or united. The research teams in one area seldom referenced other work outwith their own discipline or domain. Thus while there are a number of common concerns across the academic agendas about health and illness, and illness and employment and about young people and employment, interconnections between different fields seem to be made only rarely.

Another related but important point for this study is that the recent UK literature about young people and employment rarely focuses directly on those with chronic illness. There is disease-specific information available for some disorders but only a few studies seem to have been published that chart the experience of employment among those with a range of chronic conditions. On the other hand, there is a growing body of research emerging about disability and employment, some of which includes young people. This runs alongside an explosion of policy documents released by the UK government and Scottish Parliament looking at welfare to work initiatives for those not in paid employment.

A third issue to note is that chronic illness is a broad but distinct grouping in its own right (although this point is contested in the literature: see, for example Bury and Shakespeare and Watson (Bury, 1996; Shakespeare and Watson, 2002). Chronic illness is not totally synonymous with disability nor does it fit well with social exclusion or with any other employment-related policy category. Disability may frequently intersect with chronic illness but it will not encompass it entirely. Similarly, studies on

youth and social exclusion recruit from a wide population base, some of which may include individuals with chronic illness. The difficulty with such research is in separating out the common issues that affect whole samples from those that primarily concern those with a long term condition.

For clarity and because the literature reflects different academic fields and/or theoretical viewpoints, chronic illness and employment is reviewed within each specialty so that research in medical sociology is examined separately from literature from an occupational health perspective and so on. This approach precludes an interdisciplinary presentation around particular themes or topic areas. Work for those with long-standing illness is in many ways an under-researched and under-theorised area. As a consequence, mechanisms such as inclusion, exclusion, marginalisation or discrimination and the relationship between concepts for these groups of people have yet to be fully integrated into academic study.

Decisions about policy and practice in the public sector are increasingly driven by consideration of the best available evidence. When the evidence is as dispersed as it is with chronic illness and employment, then the tendency is to stick to either one or other line of enquiry. A more eclectic approach, however, could help to push forward the research and policy agenda for this topic. Such a framework would require a broad, critical theoretical understanding alongside a solid empirical base. It might also serve to generate further debate on the interface between chronic illness, social exclusion and disability and establish a dialogue between various subsets within sociology, disability studies, psychology, occupational health as well as engage the attention of policy makers themselves.



## 2.4 Medical sociology

Chronic illness has long been a research topic in medical sociology particularly in Britain and in the USA. Early work within this discipline was taken up with debates over Parson's concept of the sick role (Parsons, 1951) and the notion of disability as 'social deviance' (Friedson, 1965) or as 'spoiled identity' (Goffman, 1963). With a series of articles contained in one volume, 'Chronic Illness and the Quality of Life', Glaser and Strauss focused on the types of action and strategies adopted by 'actors' in managing chronic conditions (Glaser and Strauss, 1975). As Williams noted, this publication heralded a change in the chronic illness literature from a view of individuals as essentially passive, succumbing to stigmatising labels and facing 'crisis' encounters, to perspectives that emphasised the negotiated realities of everyday lives (Williams, 1999).

In the past two decades, there has been an explosion of articles on disease-specific conditions exploring the life-worlds of those with a wide range of different diseases, at different stages of illness and in different contexts. This interest in lay knowledge has been part of the conceptual shift in medical sociology towards adopting an 'insider' viewpoint. Conrad insisted that in order to understand the chronic illness experience fully, researchers must focus on the *"insider's perspective (as this captures) the subjective experiences of living with, and, in spite of illness. It (directs attention) specifically on the perspective of people with illness and attempts to examine the illness experience in a more inductive manner (Conrad, 1990) (p. 1259)"*.

Many researchers have taken up Conrad's call, and using qualitative methods, have explored the experiences of those with insulin dependent diabetes (Rajaram, 1997), cystic fibrosis (Lowton and Gabe, 2003), arthritis (Pinder, 1995), cancer (Mathieson and Stam, 1995) among others (epilepsy: (Scambler and Hopkins, 1986); COPD: (Williams, 1993) and Parkinson's Disease (Nijhof, 1995). Some authors (Bury, 1982; Charmaz, 1983) and (Williams, 1984) using primary data have developed conceptual frameworks

to understand chronic illness better as a phenomenon. These three researchers in particular have been particularly influential in generating debate (see section on Disability Studies) and in spearheading theoretically informed approaches in the study of chronic illness.

In a review of impact of papers in sociology, Armstrong confirmed the importance of these articles and their continued relevance for today's researchers as measured by the mean citation score and the cumulative number of citation counts since they were first published (Armstrong, 2003). All three authors reflect central concerns of the chronic illness experience; the interdependent nature of the body, self and society, the importance of the age and stage in the life-course at which a person becomes unwell and the need to look at an individual's whole biography in order to appreciate the variable ways in which people live with long-term conditions (Lawton, 2003).

Bury drew upon information obtained from 30 semi-structured interviews with newly diagnosed individuals with arthritis (age range 25-64) to advance his argument that chronic illness constitutes a major disruptive experience (Bury, 1982). He terms the onset and experience of illness as 'biographical disruption' that undermines taken-for-granted assumptions and involves a fundamental revision of a person's identity and biography. Bury suggests that disruption takes place on many different levels, from a renewed consciousness of bodily experiences such as pain and stiffness and the tenuous nature of one's existence to the practical consequences of illness on relationships and social support networks. His observation was that a diagnosis of arthritis marks "*a biographical shift from a perceived normal trajectory through relatively predictable chronological steps to one fundamentally abnormal and inwardly damaging*" (Bury, 1982, p. 71). As a direct effect of functional impairment and embarrassment wrought by illness, Bury maintains that individuals restrict their social terrain to familiar territory. It is argued that the strength of one's ability to mobilise resources (social, economic and

psychological) may affect how chronic illness is experienced within family life and in the workplace (Bury, 1982).

From a symbolic interactionist perspective, Charmaz interviewed adults (number = 57; age range 20-86) with a variety of chronic illnesses, particularly focusing on those who were housebound and debilitated (Charmaz, 1983). She developed a concept of 'loss of self' describing how being ill over a prolonged period leads to a restricted, socially isolated and discredited life that makes individuals question their own self-worth and expectations for the future. The accumulation of such physical and psychological strains engenders a "crumbling away" of *"former self-images without (the) simultaneous development of equally valued new ones"* (Charmaz, 1983 p. 168). Each loss of self in one area produces losses of control and action in another which result in spiralling consequences such as loss of productive function, financial crises, family stress, stigma and dependency.

In an interview study with thirty "seasoned professional" adults with rheumatoid arthritis (age range 26-68), Gareth Williams explored the ways in which individuals' beliefs about the causes of illness can be read as narrative reconstructions of their changing body, identity and relationships to society produced by the "fragmentation" of chronic illness" (Williams, 1984) (p. 177). The impact of diagnosis and effects of illness over time, William argued, causes recalibration of one's biography and this strategy allows illness to be understood both in terms of past experience and a potentially purposeful trajectory for the future. In seeking to explain illness, Williams' informants often pointed to what they saw as significant events from their past, such as a negative or unsafe work experience or death of a relative. Such accounts, can be read as attempts to *"repair ruptures between body, self and the world by linking up and interpreting different aspects of biography in order to realign present and past and self with society"* ( Williams, 1984 p. 197).

Bury, Charmaz and Williams all provide analytical frameworks from which to construct meaning out of people's experiences of chronic illness. These authors have had a profound impact on subsequent research undertaken in this field over the past 20 years. Indeed, their continued influence on empirical work published today can be seen widely in the current literature (for example, see the use of Bury's and Charmaz's concepts in papers by Walker et al. (Walker et al., 2005) and Kinmond, K. et al. (Kinmond, 2003) and the use of William's narrative reconstruction argument in Harden (Harden, 2005). These three authors (that is, Bury, Charmaz and Williams) have been successful in extending their grasp of the chronic illness experience beyond the immediacy of their particular areas of investigation to contribute to a general understanding of what it means and what it feels like to be chronically sick (Lawton, 2003).

However, a body of work is emerging which is beginning to challenge some of the hitherto accepted canons of this field. These criticisms have been on several fronts, some of which will be discussed in subsequent sections (postmodernist approaches and disability studies) but all seek to question the predominantly negative portrayals of chronic illness as depicted by these studies. The pervasive conceptual frameworks of Bury, Charmaz and Williams are predicated to a large extent on an adult-onset and crisis model of illness i.e. denoting a change of circumstances wrought by a decline from a 'normal' state of health to one of illness. It is unclear whether diseases may be experienced as less disruptive and less damaging to those who have no recall of a life free from ill-health. The impact of conditions in childhood may become so integral to an individual's embodied sense of self that managing the effects of illness or 'crisis' episodes might be perceived as commonplace and normal (rather than normalised).

The insidious and progressive effects of long-term conditions, we are told, causes “fragmentation” and “losses to self” which are “inwardly damaging” to individuals. Research on illness experiences of older adults, however, reveal that age, biography and life experiences appear to mediate perceptions of symptoms and responses to illness. Sanders et al., for example, found that the aches and pains associated with osteoarthritis were viewed more as biographically anticipated events than disruptive experiences for the informants in their sample (Sanders et al., 2002). Similarly, Pound et al. in an exploration of those affected by stroke in the East End of London, remarked that whilst this illness often had a considerable effect on participants’ lives, it was frequently perceived as ‘not that bad’ and a natural consequence of years of cumulated morbidity and material hardship due to age, background and biography (Pound et al., 1998).

A related point also is that illness itself is often the focus of attention in empirical studies. Accounts by respondents can then imply a causal relationship between the onset of symptoms and effects of disease on the one hand and previous lives untroubled by adversity on the other. This may be a somewhat simplistic rendering of life in late modernity as Williams terms it when all individuals are faced with endless cycles of biographical reappraisals, revisions and health concerns that generate uncertainty (Williams, 2000). There is a need then to extend the lens of scrutiny within the sociology of chronic illness to both ends of the life-course to include those affected by disease in childhood as well as those who are the ‘oldest old’ (Williams, 2000). In addition, May observes that researchers have in the main focused on episodes of specific illnesses rather than lifetime careers of those with long-term conditions (May, 2005). This has had the effect of highlighting and emphasising intensive experiences of disease instead of the everyday reality of lives in which chronic illness features as ‘background radiation’ among people’s efforts to accommodate and adapt to the life-worlds to which they belong.

## **2.5 Postmodernist perspectives**

Kelly and Field asserted that in contemporary Western society (writing in 1998), the world has become more diverse with a loosening of social structures and a concomitant fluidity in work roles, cultural identity and class divisions (Kelly and Field, 1998). The transition from a manufacturing-based economy to a predominantly service oriented one coupled with developments in information technology has led to the adoption of more flexible working patterns and a wider range of “explanatory discourses”. These changes to discursive practices, they argue, have widened the potential for the experience of chronic illness to be perceived in less deterministic terms (Kelly and Field, 1998).

In post war Britain, it is claimed, the identity of the chronically ill individual mirrored the core identities in the social structure, that is being sick became for many a dominant status which displaced the usual roles within work, leisure and family life (Kelly and Field, 1998). In modern industrial societies, individuals have been forced to become self-reflexive and to construct their own life styles rather than being able to accept pre-prescribed social roles and identities as guides to behaviour (Giddens, 1991). The implications of these changes, Kelly and Field maintained, is that those who have long-term conditions may have recourse to different and wide ranging illness identities that may be less coercive and constraining in post-modern than in modern times (Kelly and Field, 1998).

Freidson argued that whereas chronic illness was once almost exclusively managed by the medical profession with doctors perceived as the legitimate arbiters of that role through their professional status, their use of diagnostic skills and treatments and their ability to access wider clinical services, there has in recent years been challenges to this hegemony (Freidson, 1994). Among these include increased acceptance and uptake of complementary therapies by the public, the proliferation of self help and ‘expert

patient' groups (the CF Trust, for example, employs four expert patient advisers) and ready access to information about health concerns from television and radio through to the internet. Within the health care system itself, there have also been attempts by nurses, midwives, allied health professionals, pharmacists and others to counter the prevailing dominant position of medical staff in defining illness and treatment, though not always with success (see (Fox, 1993) and (Coombes et al., 2004).

Whilst still significant, scientific (medical) discourse is by no means the only explanation individuals draw upon to understand and manage their illness. Advances in disease management including more effective drugs may also have had a profoundly liberating effect on some people allowing the possibility of living life 'at arm's length' from an illness rather than being completely ruled by the symptoms of disease (Kelly and Field, 1998). In these circumstances, chronic illness may be perceived as just one identity amongst many that may compete at different times with other, possibly more attractive roles on offer in the workplace, in relationships, in family life and in other social spheres.

From a postmodernist perspective, Fox has also challenged the modernist readings embedded in the concept of the 'suffering self' (Fox, 1993). The focus on issues such as biographical disruption and the search for meaning and legitimacy merely serves, Fox asserts, to 'fabricate' a subject who is effectively 'trapped' within his/her body and is required to 'adjust' or 'adapt' to the limitation this engenders (Fox, 1993). It is claimed that a more reflexive interpretation is needed, one that takes better account of the context, timing, and expectations of the body and self in relation to chronic illness. Postmodernism offers another perspective from which to understand those with long-term conditions, one that is not so constrained by deterministic frameworks. It also extends the range of discourses available so that similarities of experience may be counterpoised against differences both between conditions and between individuals



with the same chronic illness. As Kelly and Field suggest, there are potentially a variety of ways of 'doing' chronic illness and of being ill which reach beyond the conventional boundaries of medicine and into a number of different fields of human activity (Kelly and Field, 1998).

## **2.6 Disability Studies**

Many disability theorists in the UK (see in particular the seminal works in this area by (Barnes and Mercer, 1996; Finkelstein, 1980; Oliver, 1990) claim that a medical model which takes as its starting point the biological reality of impairment has informed much of the historical, sociological approaches to disability. It is argued in these texts that the focus of empirical work in medical sociology has predominantly been on the functional and psychological limitations of individuals with illness and the adverse effects of these in everyday life (Barnes and Mercer, 1996; Oliver, 1990). Such accounts, sometimes termed 'personal tragedy' stories by activists, have resulted in the portrayal of people with impairments as passive and pitiful victims of circumstance.

In contrast to this medical model, many disability theorists argue that it is not illness or impairment that creates dependency but the oppressive and discriminatory structures of society itself (Finkelstein, 1980; Oliver, 1990). From this perspective, disability and dependency are seen to be caused by disabling social barriers that hinder the full participation of disabled people in social activities, including from leading productive lives. This reconfiguration of disability focuses attention away from functional limitations at an individual level toward change on a socio-political front. Disability from this viewpoint is a matter not of medical diagnosis and health care intervention but one of obtaining basic human rights. In promoting a social model approach, Oliver stated that,

*'Dependency is created amongst disabled people, not because of the effects of functional limitations on their capacities for self-care, but because their lives are shaped by a variety of economic, political and social forces which produce it.'* (Oliver, 1990, p. 94)



The importance of the social model in advancing a political agenda for disabled people cannot be underestimated. It has garnered support among activists in the British disabled people's movement and has become a reference point for those interested in furthering a social understanding of disability (Thomas, 1999). Shakespeare and Watson called the social model 'the ideological litmus test' by which disability politics is played out by activists to distinguish between organisations, policies and theorists considered to be progressive and those considered oppressive (Shakespeare and Watson, 2002).

In the last decade there have been various critiques of the social model of disability from both within and outwith the British disabled people's movement. One of the major challenges to the model has been the lack of acknowledgement towards impairment itself which social modellists have either tended to downplay or ignore entirely. Corker and French argued that the distinction made between disability, as an oppressive, socially created state and impairment, referred to in the social model as physical attribute, establishes a dichotomous relationship which valorises disability to the detriment of impairment (Corker and French, 1999). As Shakespeare and Watson discussed, this dualism sets up a theoretical inflexibility that overlooks or obscures the subtleties of the lived experience of disability (Shakespeare and Watson, 2002). In failing to engage with individual biography, that is disabled people's perceptions and attitudes, the social model undermines the discursive link between disability and impairment which can be understood only in relation to each other and in respect of specific social, economic and historical circumstances.

Disabled people then are not solely disabled by society but also disabled by their bodies and by whatever label identities they assume. Williams also pointed out that, in any case, being able-bodied is itself always a temporary state in that impairment, illness and

disability are theoretically open to everyone, particularly as populations age (Williams, 1996). One solution proposed by Shakespeare and Watson is for disability studies to take on board other perspectives, particularly those of post-structuralism and post-modernism, in order to develop a self-reflexive awareness of the various and multilayered discourses that make up disability as a discipline (Shakespeare and Watson, 2002).

Crow (Crow, 1996) has argued for the need to bring the personal experience of impairment back into the disability debate, a position which has been further endorsed by Thomas (Thomas, 1999) Corker and French, (Corker and French, 1999) and Shakespeare and Watson (Shakespeare and Watson, 2002). In a study concentrating on the employment experiences of two out of 25 adults interviewed with arthritis, Pinder revealed how empirical research can help to highlight the negotiations and 'subtle mental dialogues' that individuals with illness engage in as they attempt to gain and sustain a place in the labour market (Pinder, 1995). The detailed description of the work situations of two informants attest to the complex ambiguities that occur around the issue of work discrimination. Notably, no informant, even those who had been dismissed from their jobs, would concede that they might have been discriminated against. Pinder, however, warns against a simplistic reading of their plights and makes the point that the experience of illness and disability at work cannot be understood without bringing the individual, and the body, back into the equation as a topic for investigation (Pinder, 1995).

A recent questionnaire and interview study of 33 employed workers with disabilities in England explored the means by which disabled people manage in the workplace and the types and roles of support they receive (Roulstone et al., 2003). It was found that people made use of a diverse and complex range of strategies in order to survive and thrive at work. These included adopting behavioural strategies such as being assertive

but not aggressive to colleagues and being open about impairment, disability and any associated barriers in the workplace. Both formal and informal networks were used by individuals to provide them with practical, organisational and emotional support in the workplace. There was no single strategy that stood out as beneficial to all disabled participants in this study and the authors conclude that in general disabled workers want access to more structured and formalised support systems. A key message was for employers to become much more proactive in their management of disabled employees not only in providing environmental and technical adjustments but also in responding sympathetically to needs and making full use of flexible working policies (Roulstone, 2003).

Another interview study undertaken by researchers from Nottingham University compared the experiences of 29 young disabled adults who had both jobs and independent households with those who had either one of these or neither (Hendey and Pascall, 2002). Most participants in this sample (total = 72) were entitled to Disability Living Allowance in the middle or higher rates and were aged between 21 and 35. Employment for many of these respondents was seen as the best route to independence and social inclusion. However, securing work proved difficult for most even for those with high academic qualifications. As a result, some people resorted to taking on low paid jobs often through public or voluntary sector schemes in the hope that this would lead to something better. Benefits proved a key influence on participants' ability to obtain work. The increasing trend of charging for personal assistance made it difficult for some participants to take up employment as few were able to achieve incomes that compensated for the fall in benefits. Of interest is that respondents with both jobs and independent households most often named parents as the key to attaining these goals. Parents were valued who offered 'stringent nurture' that is if they had high expectations of their children's educational achievements, of their ability to care and fight for themselves and of their need to live independent lives.

Notably, few participants had found viable support networks beyond that of the family (Hendey and Pascall, 2002).

Banks and Lawrence undertook a research study to investigate the effect of Parkinson's Disease on labour market participation in order to identify factors that enable or prevent people with Parkinson's from remaining in or re-entering employment (Banks and Lawrence, 2003). The authors used both quantitative and qualitative methods, obtaining 327 completed questionnaires and conducting 24 one-to-one interviews. They found that 3 out of 10 participants were in employment at the point of contact and those who had stopped work since receiving a diagnosis were more likely to have been in manual occupations. For those still working, support provided by employers varied. Participants reported that they used a combination of workplace adjustments, some supplied by work colleagues, such as the offer of reduced or more flexible hours, and others, such as aids, sometimes organised and paid for by themselves. Many of those who took part in one-to-one interviews and who had heard of the Disability Discrimination Act felt that this had not been applicable to their circumstances. In spite of this, almost one in five participants reported that they had asked their employer to make an adjustment to their work to help them cope with the effects of Parkinson's Disease (Banks and Lawrence, 2003).

Burchardt provided a useful piece of research on the aspirations and occupational expectations of young disabled people (Burchardt, 2004). Using two large scale representative surveys, she combined cohort data from 569 young adults aged 18 -19 living in Britain in 1998 and 2000 and added in the experiences of 238 16 years olds from 1986. Data comprised only those identified by a parent or school nurse as disabled and did not include anyone with a learning disability. Of note was that young disabled people today expect to be offered lower earnings than their non-disabled counterparts and are also willing to accept lower wages. In general, the study showed

that whilst young disabled people held similar aspirations to their non-disabled counterparts, they tended to be less confident, less well supported and more likely to be fatalistic with respect to employment outcomes. It is surmised that by age 18, many disabled adults may well have experienced discrimination in the form of practical barriers or societal attitudes and be aware of the limitations arising from their impairment (Burchardt, 2004). The key findings of this study (which are remarkably similar to those in the following section for excluded youth) include: starting early (there is a positive association between educational attainment, positive aspirations and later success), the importance of social class background on the formation of educational outcomes, and the message that qualifications as opposed to solely practical skills make a crucial difference to the prospects of young disabled people and their confidence to succeed in the labour market.

## **2.7 Sociology of youth**

Another strand spanning sociology and the field of education is a burgeoning research literature in the UK on the sociology of youth. This field covers the transition period between adolescence and adulthood and from school to employment and includes trends in teenage employment and unemployment, youth training schemes and the experiences of both ordinary young people and those of specific subcultures, such as the Teds, Punks, Hoodies etc.

During the last decade or so, the importance of studying the everyday lives of 'ordinary' young adults has gained ascendancy. Whilst research on various youth sub-groups make valuable contributions to understanding the behaviour of some young people, the motivations and experiences of the 'invisible majority' has been the focus of major studies in recent years (Furlong and Cartmel, 1997; Jones, 2002; MacDonald and Coffield, 1991; Macdonald and Marsh, 2004; Pavis et al., 1998).



Such research does not mention young adults with chronic illness explicitly nor does it demonstrate disabled peoples' experiences but it does look at those most at risk of social and cultural exclusion. A literature review published by the Office of the Deputy Prime Minister in 2005 (Jones, 2005) explored the beliefs and actions of young adults aged between 16 and 25 specifically to inform policy development. It found, after reviewing the evidence in various parts of Britain, that the lives of young adults are changing. The transition from childhood dependence to adult independence does not proceed along a continuum but is broken down into different but interconnected strands or pathways, including a staged progression from:

- education to the labour market
- child to partner/parent
- living in parental home to forming households and starting housing careers
- dependence to independence

(Jones, 2005 p. 9)

The evidence suggests that young people might now become adult along one strand or pathway but not necessarily along another. Thus they could become economically independent through employment but still live in their parental home or be geographically independent but remain in need of parental or state support (Jones, 2005). The report also questions the validity of such a concept as 'transition to adulthood' given that the statuses associated with being an adult, that of obtaining a secure job, entering a long-term partnership/relationship, acquiring independent housing, becoming a parent, are now much more imbued with uncertainties and risk. The risky nature of gaining and maintaining these statuses has resulted in many young people having to backtrack and in so doing revert back to a form of dependence, for example if they lose their jobs, break up with a partner or have nowhere to live. It is argued that the period of dependent youth has been extended for a growing majority of young people in Britain with many taking slower routes to adulthood (Jones, 2002;

Jones, 2005; MacDonald and Coffield, 1991).

Drawing on a rich body of literature, Jones cites an increasing polarisation among young adults with regard to education, work, health, family formation and civic participation with differences in the pace, ordering and length of transitions relating to class and cultural practices (Jones, 2005). She maintains that there are two main outcomes as a result of different routes to adulthood; those of slow track and fast track transitions. For those in the slow lane, entry into employment is often delayed through further and higher education which involves taking on semi-independent statuses and requiring extended levels of parental or family support. It is noted that young people who follow this slower route may come into difficulty if they do not have middle class backgrounds (i.e. an economically viable network) to fall back on. Fast track entrants typically leave school at or before the minimum age and risk unemployment or placement in insecure and badly paid jobs. These young people may end up being economically inactive and socially excluded, the so-called NEETS of policy documents (Not in Education, Employment or Training) (Jones, 2005; SE, 2006b).

Inequalities among young people have their origins in wider social structures. Though the influence of social class has declined, it remains substantial partly because access to higher educational opportunities is not equal (Forsyth and Furlong, 2000; Marshall et al., 1997). It has also been argued that cross-cutting structural inequalities still largely determine young people's life chances in many ways (Jones, 2005). The effects of social class also interact with those of gender and race. The 'feminisation of society' resulting from increased educational achievement among women, and an increase in service industry jobs (Bynner et al., 2002; Stafford et al., 1999) has created new problems for working class young men. However, though more women than ever are obtaining degrees, this advantage is not necessarily carried through into labour market success (Meadows, 2001; WEU, 2006). There is also a variation between ethnic groups both in



participation in post-16 education and in employment outcomes (Berthoud, 1999; Jones, 2002).

Since 1997, the Joseph Rowntree Foundation has funded a programme of work in recognition of the need for researchers, practitioners and policy-makers to take a more joined-up approach to the problems of young people in the UK. The evidence from the eighteen projects funded in this programme suggests that there is a growing divide between different social groups with regard to education and employment (Jones, 2002). There has been a massive increase in young people continuing in further and higher education but some working class young adults are missing out because they do share a belief in the benefits of an extended education and/or because they cannot afford to study rather than work (Jones, 2002).

Patterns of change in youth transitions have also been affected by the modernisation of Britain's labour market in recent years. Despite economic growth and a decline in the numbers of young people available for work, a core of youth unemployment remains (Jones, 2005). Along with a substantial drop in the size of the labour market for young people, (Bynner et al. report a decrease from 6.5 million in 1984 to under 4 million in 1998 of those aged 16-24 years who worked or were available to work on a full-time basis), there has also been an increasing degree of marginalisation of employment for young people (Bynner et al., 2002). Many of the jobs traditionally taken by school leavers such as trade apprenticeships and clerical work have now been largely replaced by sales or personal service occupations that are often insecure, low-paid and part-time (Bynner et al., 2002; Jones, 2005; Stafford et al., 1999).

Research undertaken with young people themselves has found that those who leave school at 16 still hold a strong work ethic but this may be based on outdated beliefs about the kinds of jobs now available to them. In a review of a number of studies



looking at the attitudes of working class young men, Meadows found that most respondents valued and aspired to a proper job (Meadows, 2001). They still thought in terms of manual work and had no appreciation that they might not be able to achieve and maintain a traditional pattern of working class life in which they were the main breadwinner. These young men emphasised jobs over education despite the reality of their jobs often being temporary, casual or less than full-time (Meadows, 2001).

According to Johnson and Burden, the concept of a 'job for life' no longer holds credence (Johnson and Burden, 2003). In a descriptive study these authors found that many of the young people interviewed (number = 30) saw their early labour market experience in instrumental terms, that is as a stop-gap until career ideas had developed or simply as a way of earning money to pursue other ambitions such as travel. It was notable that employers (number = 39) who were also contacted in the course of this research tended to have very limited recognition of the specific needs of young recruits, particularly those entering their first job. Most adopted a 'one size fits all' induction policy for all employees that may, in some cases, be to the detriment of young people (Johnson and Burden, 2003).

Family background remains a critical factor in predicting outcomes in the labour market. Bynner et al. compared two large samples of young people, one of which reached the age of 25 in 1983 with the other reaching this age in 1995. The research team found that young people in low-income households at 16 were much more likely to be unemployed or out of work in their early 20s than their counterparts from higher-income families (Bynner et al., 2002). Those who managed to secure employment were often to be found later in low-paid jobs and at the lower end of the earnings distribution. Furthermore, the psychological health of young adults, especially among women, appears to be declining relative to 12 years ago (reporting in 2002). Self-reported depression was associated with spells of unemployment, poor qualifications

and early exit from school (Bynner et al., 2002).

Recent policy developments have been aimed at improving the educational qualifications and thereby expanding the job prospects for young people. Stafford and colleagues argued that there is a need to consider afresh the range of employment initiatives put in place since 1997 particularly those under the 'New Deal for Young People' (Stafford, 2005). The evidence presented by the study undertaken by Bynner et al. relates to the continuing and growing disparity between those young people who gain access to and benefit from the expansion of further and higher education and those who do not (Bynner et al., 2002). The problem is complex and it is argued that any policy initiative will need to refocus attention on the increasing marginalisation of those who cannot and will not benefit from improved educational opportunities across the UK (Stafford, 2005). This argument is taken further in Chapter 7 in relation to the findings of the study and in considering the outcomes of the research respondents at the point of interview.

## **2.8 Occupational health**

Over the last 5 years an increasing literature has been developing about employment issues among people with chronic illness from an occupational health perspective. Much of this research derives from the Netherlands but is also acquiring an international focus with an aim to investigate the extent of labour market participation and the factors which contribute to work disability for individuals with long term conditions. The term 'work disability' is used in this literature to refer to employment problems that arise in connection with chronic health conditions, including for example the inability to participate fully in the labour market and/or difficulty in performing a role expected of a person within a particular work context. Thus an individual with severe diabetes who has stopped working as a labourer because of his health status would be considered to have a work disability as would a nursery nurse who is still

working but limited in performing one or more key aspects of the job, such as taking outdoor games (Lerner et al., 2005). It is worth noting that an occupational health perspective takes an individualistic medical approach to the issue of chronic illness and work which is somewhat at odds with the disability studies literature and that reported under sociology of youth.

One study with survey data collected in 1998 sought to compare a patient population sample of 1266 aged between 15-64 with reference data published by the Dutch government (Baanders et al., 2002). The authors found that 45% of those with chronic illness were involved in paid work in contrast to 60% of the general population in the Netherlands. Pain, fatigue, problems with motor control and/or cognitive functioning were significant factors in predicting work disability. Disease category or diagnosis alone, however, was not correlated with unemployment. It was confirmed by multivariate analyses that being employed was more likely in younger and more highly educated individuals with chronic illness.

A subsequent research project using information from the same data source but in the following year (1999) set out to determine how many working people in the Netherlands encountered problems at work as a consequence of their disease and how many received adjustments to overcome specific difficulties in job performance (Baanders et al., 2001). A distinction was made in the questionnaire between immaterial adjustments in the workplace which included reduced working hours, job reassignments, help from colleagues and material adjustments, such as the installation of specialised equipment or assistive devices, improved accessibility of the building and re-training opportunities. This study reported a very low level of workplace adjustments in place for much of the sample, a situation which has also been observed in the US (Schall, 1998) although UK research (Munir et al., 2005) reveals a somewhat higher uptake at least amongst those with asthma, arthritis and musculoskeletal

conditions. It is unclear from these studies whether the low level of workplace adjustments is the result of lack of knowledge or reluctance on the part of employees or negligence by employers or a combination of some or all of these factors.

Receiving appropriate support from line managers and employers requires their knowledge and understanding of an employee's illness. Many diseases are not perceptible to others and employees may choose not to reveal personal information. The choice of whether or not to disclose a chronic illness has been found to be complex and influenced by a host of factors including stigma, type and severity of illness, and access to support (Greene, 2000; Vickers, 1997). In a cross-sectional questionnaire study of 610 UK university employees, Munir et al found that discrete self-management factors predicted different levels of disclosure (Munir et al., 2005). The greater the impact of chronic illness on the individual, the more likely it was that information to employers about illness would take place. Occupational status did not emerge in this study as a significant predictor of disclosure except for academics who were least likely to disclose an illness, a finding which is consistent with research on other professional groups (Beatty, 2001; Brown et al., 2002; Burstrom et al., 2003). These authors hypothesise that professionals compared with other occupational groups may be less likely to disclose illness due to pressures on them of maintaining competence, reliability and credibility.

Allen and Carlson explored the experiences of people with a disability who had made successful employment transitions after loss of work capacity (Allen and Carlson, 2003). A purposive sample of 13 was recruited and participants interviewed using qualitative techniques in Brisbane, Australia. The authors found that concealment of health status was frequently and spontaneously mentioned by 9 of the participants. A number of reasons were proposed for concealing a disability or limiting the situations in which it was disclosed. The main motivations behind concealment were: to preserve self-esteem,

to avoid emotionally hurtful responses, to circumvent negative employer attitudes regarding productivity and a cultural norm not to complain (Allen and Carlson, 2003).

Using secondary data analyses, Lerner et al. concluded that services available to help working adults with chronic illness in the US were both narrowly focused and fragmented (Lerner et al., 2005). A variety of public and private sector programmes were identified that addressed prevention of work disabilities relating to occupational illnesses or injuries but few provided help specifically for adults with chronic illness. The services available were typically not geared towards addressing work disability *per se* and those that were occurred at the tertiary level (that is, after the person had stopped work). Examples of initiatives were cited that seemed to show promise for preventing or minimising work disability. However, a lack of co-ordination in practice often undermined efforts and became a significant barrier to progress (Lerner et al., 2005).

These studies indicate that employment in people with chronic illness is associated with youth and educational attainment. According to the literature within this discipline, adjustments in the workplace seem to be a somewhat hazardous practice but perhaps more common amongst those with certain long-term conditions. Disclosure of chronic illness at work would appear to be dependent on whether access to support is perceived to be available. These issues will be discussed more fully in the findings of the study (Chapters 5 and 6) in relation to the reported actions and experiences of research respondents.

## **2.9 Psychological approaches to chronic illness**

There is a long history of interest in psychological factors that affect illness. Traditionally, psychological research concentrated on the negative psycho-social corollaries of illness in childhood; the so-called 'high risk' manifestations of emotional

and behavioural disturbance (Cadman et al., 1987), family upheaval (Eiser, 1990b) or the pathological aspects of illness (Johnson, 1988). In fact, the evidence that chronic illness carries a substantial risk to a child's physical and emotional growth and development has been heavily criticised on methodological grounds (Blair et al., 1994; Shepherd et al., 1990). More recently, a number of researchers have begun to contradict the notion of disabled children as passive and incapable of social action (Banks et al., 2001; Davis and Watson, 2001). Others have highlighted children's coping strategies (Eiser, 1990b), their resilience to illness (Kashani et al., 1988) and the concept of individual competence (Midence, 1994). It is now generally accepted that most children and young adults with chronic illness do not develop clinically significant psychological problems throughout their lives and are able to adjust to the stresses associated with illness (Midence, 1994; Sharpe and Curran, 2006).

In studies of adults' psychological responses to illness, there is evidence that beliefs about identity, consequences, control, timelines and causes of illness are important in determining attitudes to health status and emotional well-being (Buchi et al., 1998). Those who identify strongly with an illness identity, exhibit passive coping styles and view their condition as long-term and serious seem to have poorer psychological outcomes (Sharpe and Curran, 2006; Weinmann et al., 1996). In contrast, seeking social support and believing that illnesses are controllable are associated with better adjustment responses (Scharloo et al., 1998). It is also well documented that some people manage to maintain good psychological functioning in the presence of considerable physical incapacity (Andrykowski et al., 1993; Sharpe and Curran, 2006). Such evidence is supported by qualitative studies that reveal that when diagnosed with illness, individuals change their expectations about what is important given their new circumstances (Juraskova et al., 2003). It would appear, therefore, that people are often able to maintain an acceptable quality of life despite declining physical health through a process of biographical recalibration and re-definition of priorities and goals.

In terms of employment, there is a wealth of evidence that being at work is largely beneficial to physical and psychological health. In a literature review published by the NHS Health Development Agency (Bartley et al., 2005), the authors examined the mechanisms by which work, non-work and health appear to be related. First, jobs that provide fulfilment and allow individuals control over their working lives seem to confer significant health benefits when measured by overall mortality. However, employees experience higher rates of morbidity and mortality when their work provides little room for individual discretion and self-direction. Finally, absence of work in the form of unemployment would appear to produce the worse outcomes of all with respect to social and economic impacts and adverse physical and psychological health effects.

Notably, being out of work in the early years of potential employment is associated with considerable negative consequences, which can have a lasting effect over the remainder of a person's life-course (Wadsworth et al., 1999). When looking at why individuals drop out of the labour market, the single, most commonly cited reason is long-term sickness and disability. The direction of causality, however, is still an issue for debate, that is whether being unemployed causes a deterioration in health or if the sick are more likely to be out of work. Importantly, much of the available evidence in this field deals with the concept of unemployment rather than worklessness in its broadest sense (McClean et al., 2005). It is not known, for example, whether being out of work is necessarily detrimental to young adults with chronic disease or disabled youth, except on purely economic grounds. The significant shift in UK policy towards welfare to work initiatives, such as the New Deal for Disabled People, Pathways to Work, and the Framework for Vocational Rehabilitation, provides an imperative to understand more about the relationship between employment and health for these groups of individuals. As McClean et al. make clear, there needs to be further research to establish the extent to which work has a positive effect on health, perhaps drawing upon a life-



course perspective with unemployment being understood as one life event amongst many within a broader social context (McClean et al., 2005). Finally much more needs to be done in order to inform policy decisions and service provisions in the health and work arena.

## **2.10 Literature on specific chronic illnesses**

There are varying amounts of literature on employment experience for disease-specific conditions. By far the majority of these to date have been work disability studies charting the impact of diagnosis on labour market productivity (see, for example, (Frangolias et al., 2003) - CF; (Tunceli et al., 2005) - diabetes; (Verstappen et al., 2004) - arthritis). These surveys tell us that people with chronic illness are severely under-represented in the workforce. Particular attention is paid to identifying the factors associated with job status and job loss amongst these chronically ill populations.

Few published data exist on the experience of employment itself or on the vocational aspirations of young people within any of these groups. However, within the last two or three years more researchers appear to be addressing these important issues, particularly from the perspective of disabled youth (see section on Disability Studies). This section provides some information about the disease-specific conditions covered in this thesis and includes research data, where possible, on employment-related topics undertaken for these groups of people.

### **2.10.1 Cystic Fibrosis**

Lowton and Gabe (Lowton and Gabe, 2003) made the point that most empirical studies of CF have been focused on the child (Bluebond-Langner, 1996; Venters, 1981) or the family (see for example, (Whyte, 1992; Whyte, 1997). Adults with CF, however, are a growing group in the UK, increasing by about 150 per year (Dodge et al., 1997). There has been more interest in recent years in exploring adult experiences of living with CF,



particularly in terms of quality of life (Abbott et al., 1997; Staab et al., 1998) and psychosocial functioning (Blair et al., 1994; Shepherd et al., 1990). By way of contrast, Lowton and Gabe looked at how health was perceived by 31 adults with CF (14 male, age-range 18-40) living in south-east England during 1997/8 (Lowton and Gabe, 2003). In an interview study, the authors identified four concepts that described the different ways individuals talked about health in the context of their daily activities. These were: health as a 'normal' state, health as controllable, health as a distressing state and health as a release. Each adult expressed both dynamic and cyclical notions of health in relation to time (past, future and current perceptions), effects of illness (whether able to maintain functional capacity), medication taken (illness viewed as a controllable state and feeling healthy in spite of needing regular therapy) and context (different modes of coping by comparing one's self with others, maintaining a positive attitude and adapting to changes in illness). Lowton and Gabe showed then that perceptions of health in a group of individuals with long-standing illness predominantly mirror those of the lay public (Lowton and Gabe, 2003). Despite having CF, the adults in this study spoke of themselves as being healthy either at the point of interview or in the recent past. This type of research contrasts with the deficit- and problem-focused studies that have traditionally crowded the literature on chronic illness. Snap-shot images such as these also help to highlight the everyday realities of life with a long-term condition and provide a counterbalance to some of the prevailing negative, societal depictions of those who live with effects of disease.

A frequent issue in sociological research that also crops up in some of the disability studies literature relates to the distinction made between people with visible and invisible impairments. This division harks back to Goffman's theory of stigma who claimed that people with chronic illness diverge from normative expectations which leads them to use concealment strategies, that is passing as normal and covering up visible signs and symptoms (Goffman, 1963). In an interesting paper that explores the

process of managing information about illness in adults with CF, Admi challenges some of Goffman's assertions from the viewpoint of today's sociopolitical climate (Admi, 1995). She undertook a longitudinal, descriptive study interviewing 10 young individuals (16-25 years) in a northeastern US city. Admi found that disclosure of illness to others was based on a variety of complex factors including the perceived ability of the listener to deal with information and maintain appropriate, reciprocal responses. Situational aspects, such as timing, relevance and others' interest also influenced the process of information management. A variety of disclosure strategies emerged; these included display of visible signs such as making no efforts to conceal typical symptoms or daily treatments, direct telling, silent telling (situations in which everyone acts as if the other knows but the disease itself is never openly discussed) and concealment. This research concluded that managing information about CF is a dynamic, controllable and contextual process. The study revealed that each respondent over time developed a repertoire of strategies to deal with having CF with most adhering to a belief that they had nothing to hide and nothing to advertise. That is, informants in the sample did not see the need to bother themselves or others by sharing their health condition with everyone in every situation. In this way, a diagnosis of CF was not seen as central to their lives in the manner suggested by Goffman; instead the approach adopted by individuals was simply that of ordinary people who have nothing to be ashamed of or proud about (Admi, 1995).

There have been few studies of adults with CF with respect to education, employment, housing and other features of lifestyle (Walters et al., 1993). In a British survey of 1052 members of the Association of Cystic Fibrosis Adults (accounting for 56% of adults with CF in the UK at that time), Walters found that more participants had left school without any qualifications than the general population (15% with CF versus 11%) with the proportion higher in manual than professional social classes. However, individuals with CF were more successful in achieving A level (or equivalent) qualifications and

degrees. Of note, was that there was no significant difference in severity of disease between the groups who had obtained and those who had not obtained higher qualifications. Furthermore, those with qualifications of any sort were more likely to be in paid employment (59% of those with school leaving qualifications, 37% of those without) at all levels of disease severity. In terms of employment patterns, this study found that 54% of responders were working compared with 69% of the general population with weekly hours worked at comparable levels. Those respondents who did not reveal their diagnosis of cystic fibrosis at job interviews were more likely to be employed than those who did irrespective of disease severity. This finding would suggest that disclosure of health status at the point of application places the job seeker at a distinct disadvantage. One recommendation made by the author was to advise people with CF wishing to take up employment to confine information about their disease solely to confidential medical questionnaires (Walters et al., 1993).

One recent Canadian study attempted to predict work disability in CF with 73 adults by using a variety of different clinical measures (Frangolias et al., 2003). The utility of respiratory function tests, exercise capacity measures and other clinical parameters were unable to discriminate accurately between those who were and those who were unable to work or attend higher education because of CF-related health issues.

Although a large number of those subjectively work disabled had a poor respiratory threshold (as measured by  $<40\%$  FEV<sub>1</sub> predicted), appreciable numbers with similar levels of lung function were also working full- or part-time. The authors concluded that the patients they studied were largely unencumbered by their disease, and of those not attending university, the majority were employed. As such, the educational and work accomplishments of this group were indicative overall of improvements in the health status of adults with CF and were perhaps reflective of their expectations of longer term survival (Frangolias et al., 2003).

### 2.10.2 Diabetes

Employment has been a focus for many studies undertaken with those with insulin-dependent diabetes. Many of these both in Britain (Lloyd et al., 1992; Robinson et al., 1989b; Robinson et al., 1990) and elsewhere (Baker et al., 1993; Ingberg et al., 1996; Mayfield, 1999) have consistently found that being diabetic can have a profoundly negative effect on those trying to obtain and maintain work and be economically independent.

A recent longitudinal American study (Tunceli et al., 2005), for example, examined the consequences of diabetes on labour market outcomes of employed adults aged between 51-61 years. Tunceli et al. identified over 7,000 employed participants, of whom 490 reported having diabetes. After controlling for other factors presumed relevant to the decision to work, such as prevailing co-morbid conditions and specific job characteristics, being diabetic reduced the absolute likelihood of working by 4.4% points for women and 7.1% points for men. Diabetes was also associated with increased absenteeism from work and unemployment (those with diabetes being two to three times more likely to have stopped working due to deteriorating health) (Tunceli et al., 2005). Work disability therefore appears to be significantly higher for individuals with diabetes than for those without and results in a considerable decrease in earnings over a person's lifetime (Mayfield, 1999).

Research (Robinson et al., 1993) across the UK examining the academic achievements and employment experiences of young adults with diabetes (number = 224; age-range 16-21) revealed that although they experienced a greater number of health problems at school compared with non-diabetic controls, they obtained comparable numbers of GCSEs (or equivalent), A levels (or equivalent) and other qualifications. The authors also reported a lack of appropriate career advice at school for those with diabetes with no allowance being given to the effects of diagnosis on particular employment

pathways. This finding supports previous observations on young diabetics concerning the lack of vocational guidance (Johannson et al., 1979), the negative attitudes of society and the lack of knowledge about the condition among teachers and the public at large (Ludvigsson, 1976).

In an interesting study undertaken to explore employers' attitudes to diabetes and diabetic employees before the introduction of the DDA, Robinson and colleagues (Robinson et al., 1989a) found that nearly a third of employers (326 out of 1060 firms) did not know whether they employed any diabetics in their company. Smaller and middle-sized companies were more likely to be aware of the health status of individuals than larger employers. A total of 65 firms reported that people with diabetes would not be given the same employment opportunities as people without the disease. This was mainly due to the unsuitability of certain jobs for a diabetic employee within an organisation (as judged by a manager) but some employers were also concerned about the possibility of ill health or poor diabetic control. Many employers admitted to being confused about the suitability of people with diabetes for different types of employment as well as expressing some disquiet about their reliability as employees (Robinson et al., 1989a). Such findings suggest that employers require more information about different chronic conditions if they are to make appropriate decisions about offering employment to a range of individuals irrespective of health status. Failure to do so may place employers outside the law and at risk of legal action.

In a study specifically designed to look for evidence of workplace discrimination among middle-aged adults in New Zealand, Baker et al. compared 102 people with diabetes with a matched comparison group of 403 non-diabetic workers (Baker et al., 1993). There were no significant differences between the groups in terms of level of educational attainment, average duration of current employment or in the frequency of sickness absence. However, gross household incomes were significantly lower in

diabetic workers compared with non-diabetic counterparts which was not explained by the contribution of working spouses. No evidence of overt discrimination at work was found in this study although the authors concede that the age of their sample could have obscured problems experienced by younger people entering the labour market and of older individuals seeking new jobs (Baker et al., 1993).

### 2.10.3 Arthritis

There has been much research linking arthritis to loss of employment both in Britain and internationally (Reisine et al., 1989; Shanahan and Smith, 1999; Sokka et al., 1999; Yelin et al., 1987). These studies differ in their definition of work disability and in the percentage of people who become work disabled during the course of the disease. In an overview of research undertaken on this topic, Verstappen et al. found that those with arthritis who stopped work tended to be older, have fewer educational qualifications and have lower incomes prior to diagnosis (Verstappen et al., 2004). Using a life history method, work disability rates reported by Yelin et al. showed that after one year of rheumatoid arthritis, 10% will have stopped work and 90% will have done so after a disease duration of 30 years (Yelin et al., 1987). By far the majority of studies in this area, however, are cross-sectional in design and focus on arthritis in adult populations rather than those whose disease begins in childhood. It is also difficult to compare results across countries because of different labour market conditions and the different social security systems in place.

A recently reported study undertaken in the UK (Young et al., 2000) looked at the impact of arthritis on progress, function and outcome of 732 individuals with early onset adult disease (median age (IQR): 45-64) attending outpatient departments. In terms of the clinical profiles of individuals at five years, it was found that 40% did relatively well with 13% in complete remission, 44% followed a relapsing/remitting course with variable functional impairment and 16% did badly in terms of the effects of

arthritis and impact on life events. Older age at onset (defined in the study at age 60 or more) and women were associated with the worse profiles of all. However, the authors concluded that disease outcomes at five years in individual patients could not be predicted with any degree of accuracy using simple clinical measures. In this study, most people in paid employment at follow-up presentation were still working (60%); work disability due to arthritis was at 22% by five years and higher rates were reported among manual workers (Young et al., 2000).

Another UK study (Barrett et al., 2000) investigated two cohorts of adult patients (defined as 16 or over) who were economically active at the time of onset of arthritis. The first cohort (number = 160) was followed up for about eight years from 1989 and the second (number = 134) for about four years from 1994. A control group, matched for age, gender and employment status at baseline, was also identified from the local population. The authors reported that adults with rheumatoid arthritis in the study from both cohorts stopped work very early in the disease process, often before they were referred to hospital or started on disease-modifying anti-rheumatic drugs. In spite of the changing treatment pattern in arthritis over the period of the study, the rate of work disability actually increased after symptom onset from 14% at year one and 26% in year two for the first cohort to 23% and 33% in cohort two respectively. This result raises questions about what advice and support individuals should be given concerning their employment. Indeed, the authors suggest that after diagnosis working adults need a very careful analysis of their work, their workplace and their plans and aspirations for the future (Barrett et al., 2000). Any delay at this stage might potentially compromise their chances of remaining economically active as their disease progression could improve after the start of symptoms.

Packham and Hall examined the levels of education and employment in 246 adults with juvenile chronic arthritis compared to siblings and to national UK data sources



(Packham and Hall, 2002). The age range of the research sample was between 18-71 years. This study found that those with arthritis achieved better educational qualifications than both their siblings and the national average across all levels of education, from GCSEs to postgraduate degrees. In contrast, the rate of unemployment among the patient group was more than twice that of the national population. The majority of patients without work attributed their out of work status to the disabling effects of their disease. However, the predictive factors for being out of work were also related to the presence of poor coping strategies which suggests that an individual's ability to cope successfully with their illness may have a large impact on their success in the workplace (Packham and Hall, 2002).

A recent Canadian study sought to examine the coping and self-management strategies used by individuals with arthritis to maintain participation in the labour market (Gignac, 2005). The research sample comprised 492 patients from hospital and outpatient clinics who had either osteoarthritis or rheumatoid arthritis. Each participant completed a structured questionnaire with information collected on symptom severity, medication use, employer knowledge of arthritis, hours of work, type of work and work participation, coping strategies in the workplace and future expectations. The mean age of participants was 51 years and more than three quarters of the sample were women. Most were not severely limited by their arthritis and were above the Canadian median for education and income. A variety of different behavioural strategies were adopted by participants to remain employed. Expectations of continued employment were also associated with modifications of work activities as was disclosure of arthritis with one's employer. The most frequently cited behaviour was anticipatory coping which included planning and organising work activities, alternating action with rest and building in stretching and exercising into a work day. People's perceptions and expectations of remaining employed are also related to employment. Those who had more positive perceptions of their job also reported



receiving more help at work (Gignac, 2005).

## **2.11 Conclusion**

Different disciplines have taken different approaches to research the issues relating to chronic illness, young adults and employment. The increasing policy agenda on this topic brings with it opportunities to look afresh at this field and consider more theoretically informed perspectives to understand how individuals with illness fare in the workplace. Studying the actions, motivations and beliefs of a group of young adults with long-term conditions provides some insight into their socialisation to the world of work. Research, however, is a theoretical activity. The ways in which data are collected, analysed and interpreted reflects different epistemological and ontological ideas about how to understand society and social processes. The next chapter identifies the main theories used in this thesis to inform the study on young people and employment and explores how these ideas developed over time.

## **CHAPTER 3: METHOD AS THEORY: THEORETICAL ORIENTATION OF THE RESEARCH STUDY**

### **3.1 Introduction**

Research is not a neutral endeavour. It encompasses theories, paradigms and ways of thinking about knowledge and meaning. The choice of theory, although sometimes unacknowledged in research documents, shapes how researchers collect, analyse and interpret data (Alderson, 1998). If theories underlying research are not elucidated, they can confuse, obscure and even limit new insights in understandings about science, policy, and human experience more generally. By specifying theoretical assumptions, research becomes more reflexive, locating process and meaning in context and opening up new possibilities for interpretation.

Data, then, are not self-evident 'facts' gathered about a topic but reflections of the theoretical ideas in terms of which they are collected (Silverman, 1998; Taylor, 1999). Researchers differ in their view of how to study the social world and about what qualifies as valuable knowledge. For some sociologists, research is designed to make generalisations about social phenomena, creating predictions and providing causal explanations. Using this type of theory, the researcher poses several hypotheses and tests these according to experimental or quasi-experimental procedures using a carefully designed sampling strategy. Data are reduced to numerical indices which can be analysed statistically to make generalisations from the study group to other persons and places. The aim of such research is to produce objective knowledge, that is knowledge which is free as far as possible from bias and the influence of the researcher. Other sociologists argue that data and observations are theory-led and subject to different interpretations and this factor undermines the very quest for objectivity (Silverman, 1998; Taylor, 1999). These competing accounts have generated different

research methodologies, each with their own distinct set of interrelated epistemological, ontological and practical foundations (Glesne, 2006; Pawson, 1999).

### **3.2 Theoretical orientation**

Distinctions between quantitative and qualitative approaches, however, can often be at the level of theory rather than practice. Whilst positivism is usually associated with a deductive process within a quantitative paradigm and interpretivism is generally perceived as inductive using qualitative methods, these concepts are not absolute and it is possible to find the use of grounded theory, for example, within a positivist framework.

At the start of this thesis, I had intended to undertake a mixed methods research project. This approach would have involved the use of validated quality of life questionnaires as well as undertaking a series of in-depth interviews with identified respondents. On the one hand, I would have drawn on deductive reasoning based on analytical components of correlation and differences between mean levels of responses to pre-set questions and on the other, I would have been making sense of emerging data using inductive and interpretive processes. In themselves, the use of these two research paradigms would not necessarily have been problematic. I was never intending to triangulate data but had simply aspired to obtain different ways to explore values and meanings given to aspects of illness and employment among those with chronic disease. What changed during the course of collecting data was my understanding of the complexity of the topic. In particular, whilst interviewing respondents I became less and less convinced that quality of life questionnaires supplemented by qualitative material could ever effectively address how people engage with the labour market whilst managing a long-term condition. The issues that arose appeared too complex, were very often ambiguous and did not follow a coherent pattern.

In exploring this field, the individual experience surfaced as composite and dynamic that could not readily be captured by a series of predetermined, social variables, however broad in focus. As data collection progressed, I became increasingly more intent on the interviewing process and the narrative accounts of respondents and, as a result, I downgraded the task of encouraging completion of questionnaires to the first few minutes of the meeting and devoted the remainder to inductive inquiry. In fact, discussion of the quality of life questions with respondents was very often a route into more discursive conversations about the variability of illness and its impact on lives as a whole. In engaging with people and attempting to understand their perspectives and experiences, I eventually dispensed altogether with the notion of presenting a mixed methods thesis. Instead, the design of my study became more fully situated within an interpretive paradigm.

This approach maintains that in order to understand social behaviour, researchers must imitate real life and become involved in interactions which create everyday meanings (Seale, 2004; Silverman, 1998). Underpinning this methodology is a belief that reality is socially constructed, fluid and complex. What is perceived as 'real' becomes relative to specific locations and the people involved. Social life revolves around shared understandings and is maintained by interacting with others in ongoing processes of communication and negotiation. Interpretive social scientists (alternatively known as qualitative researchers) want to learn about these interactions and to discover the taken-for-granted knowledge about people and events around them.

Qualitative inquiry is an umbrella term that covers many different disciplines and theoretical positions. It has its foundations in sociology and the work of the Chicago School in the 1920s but each approach (ethnomethodology, phenomenology, life history, interactionism etc) has developed different histories, foci and philosophies (Glesne, 2006). Since the late 1990s, there has been increasing concern about the nature

of qualitative data and the epistemological methodologies adopted for analysis (Melia, 1997). Nursing literature particularly abounds with papers and special issues devoted to such philosophical applications and the particular stance adopted by the researcher in relation to the research process (see Nurse Researcher, 1999, *Journal of Advanced Nursing*, 1995, 1996 and 1998). Melia reflected upon this 'climate of methodological angst' and suggests that this fad confuses the real challenge of research which is to produce understandable accounts of 'plausible stories' (Melia, 1997).

In a similar vein, Atkinson argued that qualitative inquiry will not be served by a slavish adherence to historical accidents and arbitrary boundaries that separate methodological traditions and particular research methods (Atkinson, 1995). He insisted that we should not turn the pedagogic half truths of text-book knowledge into prescriptions for research practice. There is no clear consensus among qualitative researchers about how to handle analysis and interpretation of data. The confusing array of methodological perspectives on offer has led some authors to conflate different modes of inquiry under collective headings. Denzin, for example, uses the term 'interpretive interactionism' to encompass methods such as open-ended interviewing, document analysis, semiotics, hermeneutic phenomenology, life-history research and participant observation (Denzin, 1989). Others, such as Guba and Lincoln, articulate various epistemological processes of inquiry but do not attribute their interpretive approach to a particular philosophy (Guba and Lincoln, 1989). Lofland and Lofland and Seale assume similar standpoints (Lofland and Lofland, 1984; Seale, 2004).

By far the commonest framework for guiding qualitative research is grounded theory although this strategy has come under criticism in recent years. Dey maintained that much of the success of grounded theory has been due to it being able to answer a number of questions about qualitative research; namely how to start a study (by identifying areas of interest and avoiding theoretical preconceptions), how to undertake

it (through analytical procedures and sampling strategies) and how to stop (when theoretical saturation has been reached) (Dey, 1999). Grounded theory offers a way of developing analytical and conceptual constructions of data (Charmaz, 1990) and allows researchers to follow leads, interests and hunches as they emerge throughout the study. Over time, researchers and theorists have diversified the use of the grounded theory method; its form and content being adapted and re-interpreted to fit with epistemological differences of approach and beliefs about the nature of reality.

Grounded theory is the theoretical approach adopted for this research project. Glaser and Strauss (1967) illustrated their method for handling data in their work with dying patients from which awareness theory arose. Their argument was that theory could be developed by systematic and inductive analysis obtained from data rather than through employing logical deduction based on a priori assumptions. At the start of this study I was interested in developing theory from empirical data hence my interest in the method of grounded theory. My intention was not to produce a grounded theory study, one that adhered exactly to the tenets of the method, but rather to use grounded theory to inform theoretical development of employment experiences in young adults with chronic illness. I have therefore taken a pragmatic stance. I have used the basic tenets of grounded theory as a strategy for developing categories and analysing data but have steered clear of the more structured, rule-governed method advocated by Strauss and Corbin (Strauss and Corbin, 1990). The latter proponents promote a paradigm model to guide data collection and analysis which involves identifying links between categories and sub-categories. According to Glaser the use of such a hierarchical coding structure runs the risk of 'forcing the data' i.e. developing categories that are not supported by the available evidence (Glaser, 1992). My slant has been to take on the essential characteristics of the method; those of formulating general research questions, developing analytical memos, through coding and categorising the data using the constant comparison technique to integrate research findings with

literature at a late stage; without allowing the various inconsistencies of grounded theory to obscure the outputs of research, those of producing 'plausible stories'.

### **3.3 Grounded theory: origins, evolution and criticisms**

Glaser and Strauss first promulgated the grounded theory approach in 1967 in their book, 'The Discovery of Grounded Theory: Strategies for Qualitative Research' (Glaser and Strauss, 1967). The authors since developed their method along different lines with Strauss and Corbin's work, 'Basics of Qualitative Research', gaining greater prominence among UK researchers (Strauss and Corbin, 1990). This latter text has received a number of criticisms not least by Glaser himself who has argued that the method espoused is too prescriptive and procedurally-led (Glaser, 1992). As Bryman asserted, against such a background it is difficult for the researcher to write convincingly about the essential ingredients of grounded theory (Bryman, 2001). Bryman himself distinguishes between tools and outcomes of the method and provides a coherent summary for students to absorb (Bryman, 2001). Silverman offers a simplified model of grounded theory in three stages; creating categories, 'saturating' categories to assess their relevance, and developing categories into a theoretical framework (Silverman, 2000). Most commentators, however, remark that good research and illuminating data analysis is not just a matter of being thorough methodologically but also requires developing theories based upon a consistent model of social reality (Dey, 1999; Silverman, 2000)

While the originators of grounded theory debated their method, others have sought to defend and define the central tenets of the framework. Denzin and Lincoln consider the grounding of theory through data-theory interplay, the making of constant comparisons, asking theoretical-oriented questions, theoretical coding, and the development of theory to be its prime features (Denzin and Lincoln, 1994). Several researchers make the point that it is difficult to find worked examples of grounded



theory in action. In spite of the frequency with which it is cited, many studies pay lip service to the method or show only selected facets of the strategy in operation (Bryman, 2001). Other limitations levelled at the method include doubts about its claim to generate theory, the loss of narrative flow caused by fragmentation of data and a conceptual confusion over concepts and categories (Bryman, 2001).

Charmaz also argued that grounded theory is associated with an objectivist conception of knowledge in that it aims to uncover a social reality which is independent of human action (Charmaz, 2000). Indeed, much of the language and justifications of grounded theory in Glaser and Strauss' (1967) *Discovery* text are couched in the terminology of modernism or objectivism. The authors assume a reality of an external world and take for granted a singular dominant perspective on emerging data analysis. From a constructivist perspective, however, research is a created process that takes place from the interplay between respondents, data (transcripts that are themselves a construction) and their interaction with the researcher. This viewpoint takes its premise from the idea that people create meaningful worlds through dialectical processes, that is that social objects and their meanings are socially constructed. Whether this constructionist position stands in contrast to grounded theory is still open to debate. Charmaz (2000) put forward an argument for constructivist grounded theory highlighting three main issues: first, that grounded theory strategies need not be prescriptive or rigid (as indicated by Glaser and Strauss in their 1967 text); secondly, that a focus on meaning enhances interpretive understanding; and lastly, that grounded theory can be adopted without taking on positivist leanings. The approach adopted in this study is that of a constructivist grounded theory as proposed by Charmaz (2000). Unlike objectivism where knowledge is sought by methods that are viewed as impartial and certain, the constructivist view proposes that there are multiple social realities. In other words, that meaning can never be entirely fixed but is always open to interpretation and can change.



Another strand of criticism is expressed by Coffey and Atkinson who object to the narrow analytic strategy imposed by a heavy reliance in grounded theory on coding as a first step (Coffey and Atkinson, 1996). They feel that such a procedure deters the researcher from engaging with the nuances and subtle meanings of textual data which in turn compels an exclusive interpretation. This, they argue, is further encouraged by the use of code-and-retrieve computer software packages that are explicitly linked to a grounded theory style of analysis (Coffey and Atkinson, 1996). Against this argument, Kelle maintained that techniques for indexing or cross-referencing are used by all qualitative researchers and it is up to the analyst to assume or reject the singular narrative voice proposed by Glaser and Strauss (Kelle, 1998).

### **3.4 Grounded theory: core ingredients of the method**

In spite of its critics, grounded theory remains an influential and rigorous strategy for undertaking qualitative research. The main features include theoretical sampling, coding and categorising data using the constant comparison method, memo writing and theory generation, all of which occur concurrently throughout a project. Emerging analysis influences subsequent collection and this process continues until categories are clearly defined and validated. The method is demanding and often requires flexibility and adaptability on the part of the researcher because contingencies such as time, resources and ethical constraints can predominate (Duffy et al., 2004; Jeon, 2004)). When modifications occur, it is important to provide an audit trail of decisions undertaken in order to make explicit which and in what ways research processes have been altered from the prescribed method.

Whilst procedures are designed to give rigour to a study, slavish adherence to rules can undermine creativity and flexibility. Indeed, Glaser, in his well-recorded disagreement with Strauss asserts in his text, 'Emergence vs forcing' (Glaser, 1992) that the method promoted in 'Basics of Qualitative Research' (Strauss and Corbin, 1990) does not

amount to grounded theory at all because the coding scheme is too prescriptive. There is an inherent danger, however, in championing one standpoint over another. What seems more constructive for researchers is to report the various principles of the method in order to show how the various processes of data collection, analysis and interpretation have been carried out to construct theory. Whether a study constitutes grounded theory as promulgated by one or more of the major protagonists seems in the end to be a rather secondary consideration. The primary issue should be about the research processes themselves and the account of those processes, in determining the clarity and thoroughness of the method adopted for the study.

### 3.4.1 Theoretical sampling

Sampling in qualitative studies is generally considered to be a minor concept. It has a different purpose from that of quantitative methods which aims to ensure generalisability of study findings; in qualitative research the main objective is to develop theory. Most qualitative projects comprise convenience or purposive samples because the case or cases themselves are the prime focus of interest. In grounded theory, an important aspect of the method is theoretical sampling.

Theoretical sampling is defined by founders of the approach as *'the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges'* (Glaser and Strauss, 1967) p. 45). Theoretical sampling then is the process of actively searching for informants and/or other sources of data to provide the best possible information about a research topic. The aim is to select those respondents most likely to have sufficient knowledge and experience in the area under study. In their seminal book Glaser and Strauss (1967) provide initial guidance for theoretical sampling but develop the concept more fully in later texts, Glaser in *Theoretical Sensitivity: Advances in the Methodology of Grounded Theory* (Glaser, 1978) and

Strauss and Corbin (1990) in *Basics of Qualitative Research* (Strauss and Corbin, 1990). They maintain that sampling should be founded on a generalised perspective rather than one based on preconceived theoretical views.

Data collection should begin with a fairly random group of people who have nevertheless experienced the phenomenon under study. Thereafter, sampling ought to continue cumulatively as the researcher moves to new study settings or locations in order to pursue areas that arise from the initial study. Selection, however, may also refer to decisions made to focus on specific types of people, activities or events guided either by the needs of the research or through pragmatic considerations (Jeon, 2004; May, 1999). In this way, recruitment becomes dependent on emerging findings and the requirement for theoretical elaboration and data saturation. Due to time constraints and ethical approval being confined to one hospital location, selection of respondents in my project did not conform to the definition of theoretical sampling as provided by Glaser and Strauss. Recruitment was confined solely to a geographical area served by the acute hospital trust, albeit one that encompassed a wide and diverse range of environments and localities. Some attempt, however, has been made to sample respondents from both sexes and with different types of chronic illness although further work in this area would be useful. May suggested that it is possible to develop theory without necessarily having to collect additional data in a variety of settings (May, 1999). As Jeon pointed out, in any event, the adequacy of theory depends not only on the amount of data gathered but also on its quality and the rigour of analysis undertaken (Jeon, 2004).

Glaser and Strauss do not discuss in detail how data should be collected in grounded theory studies (Glaser and Strauss, 1967). Only cursory guidance is provided although listening to respondents tell stories particularly in the early stages of research is deemed important. The use of semi-structured interviews enables the researcher to

explore topic areas in depth as well as pursue ideas of particular significance (Jones, 2004); as such this method would appear consistent with a grounded theory approach. One of the central tenets of the method is concurrent data collection and analysis so that emerging hunches in early interviews can be explored and tested in subsequent ones. As a consequence the interview guide cannot be fixed or predetermined in a grounded theory study; it proceeds from a broad list of general questions to a more focused schedule as concepts require verification or modification accordingly.

### 3.4.2 Theoretical sensitivity

In order to understand what is meaningful in data, the researcher must acquire theoretical sensitivity or the capacity to separate what is pertinent to a topic from what is irrelevant (Strauss and Corbin, 1990). This type of critical insight can arise from a number of sources; from published literature, from personal or professional experiences but should increase and develop more fully through immersion and repeated interaction with the study data. In fact, scholars of grounded theory warn against using pre-existing conceptual constructs particularly for new areas of research (Charmaz, 1990; Glaser and Strauss, 1967; Strauss and Corbin, 1990). Rather the aim is to *'put together categories in new rather than standard ways' so that phenomena are explained 'in the light of the theoretical framework that evolves during the research itself'* (Strauss and Corbin, 1990), p 49). In a later text, Strauss and Corbin argued that prior knowledge should be used to inform analysis but not to direct it (Strauss and Corbin, 1998). Glaser also stressed that grounded theorists should do their own analytical work; if concepts are borrowed from literature then they must merit a place in the analysis for they have no inherent right to it (Glaser, 1978).

Grounded theory then is for the discovery of concepts and hypotheses, not for testing and replicating them. After data have been collected, coded, compared and analysed and the theory seems sufficiently grounded, then the researcher may begin to review

the literature in the substantive area in depth and relate that evidence to his/her own work. Where there is little or no research in a particular area, grounded theory can generate relevant concepts or models; at other times the method can organise, transcend or synthesise different existing ideas into an overarching theory (Glaser, 1992).

### 3.4.3 Coding and categorising data

Glaser (1978) advocated a two step coding process as opposed to the more complex series of operations proposed by Strauss and Corbin (1990). Codes are perceived in grounded theory as the 'building blocks of theory' (Glaser, 1978), they are conceptual labels created by the researcher for the purpose of grouping events, discrete incidents and other phenomena in the data. The first phase of coding involves a line by line (or usually an incident by incident) appraisal of the data, assigning descriptive tags and examining each fragment of transcript for meaning. This process is both dynamic and iterative. It includes sorting and classifying lines of data in several ways, generating new codes as successive interviews reveal different events, and comparing the properties or dimensions of each code with one another.

The second coding phase is termed theoretical coding (Glaser, 1978). This stage is a progression of the method whereby links between codes and properties are gradually built up and integrated. Codes which have similar themes and patterns combine to form categories. These become referential and descriptive sets that contain specific characteristics or dimensions to explain events or processes in the data. As Glaser explains,

*'Theoretical coding is to conceptualize how the substantive codes may relate to each other as hypotheses to be integrated into the theory.'* (Glaser, 1978) p.72

Categories can be either *in vivo*, that is taken directly from respondents' words or theoretical, derived from the researcher's own construction of concepts. Analysis is generated by the use of the constant comparison technique which helps to develop properties by drawing distinctions between incidents, codes and categories through asking questions of the data. Properties of each code and category are determined by defining their pertinent characteristics; such as under what conditions do they apply and how do age, sex and educational experience, for example, interact in any given circumstance. The constant comparison method enables the researcher to generate theory grounded in the data rather than through preconceived ideas and helps to stimulate conceptual thinking about categories themselves.

Glaser and Strauss (1967) suggest that researchers look for a core category in their data. This variable should represent the key issue of the research and be able to integrate and account for most of the variations in events. My analysis has not followed this theoretical construction. The search for an overarching category, one that could encompass and explain all others, proved obstructive during immersion with the data and unnecessarily restrictive. Strauss and Corbin (1990) stated that it is possible to have more than one core category and indeed the story line of this project fell more easily into two broad topic areas: management of illness among young adults with chronic illness and employment experiences. These concepts and their themes are provided in two results chapters (Chapters 5 and 6) to illustrate the dense and interrelated patterning of the data.

#### 3.4.4 Memo writing

In grounded theory, memos represent written documents of analytical ideas, theoretical notes and thoughts that develop during the course of the research. As such, they evolve in complexity as the study progresses but serve an important function in the interplay between data collection and analysis. Writing memos help the researcher

become more reflexive about the research and provide threads of meaning that can be sorted, ordered and integrated into codes and categories at a later stage.

### **3.4.5 Generation of theory**

Glaser and Strauss (1967) assert that two types of theories (both middle range in that they fall between the minor working hypotheses of everyday life and the all-inclusive grand theories) can be developed using grounded theory; formal and substantive. Formal theories are more general than substantive theories and have greater explanatory power; they deal with conceptual areas of enquiry such as illness experience. On the other hand, substantive theories concentrate on specific social processes and are developed from narrower empirical studies, such as the management of care among young adults with chronic illness. The process of generating theory requires interaction with data, memos to aid conceptual thought and integration and synthesis of categories. Writing analysis is then relatively straightforward since themes (categories and codes) and their interactions provide headings or titles and the coded data provide illustrative examples.

## **3.5 Symbolic Interactionism**

Grounded theory is founded on the theoretical premise of symbolic interactionism. This theory was first proposed in the 1930s from the writings of George Herbert Mead and Charles Cooley and was later developed by Herbert Blumer in the 1960s. It rests principally upon three basic principles: that people possess the capacity to think and be reflexive, that individuals act towards one another on the basis of shared symbolic meanings, and that social life is maintained by people interacting according to chosen behaviours rather than being controlled by large-scale social processes.

Mead drew attention to the human ability for self-consciousness and self-reflection that enables actors to be both subjects and objects of themselves (Mead, 1934). Cooley



further explored this idea in his concept of the 'looking glass self' whereby a person's perceived image is also transformed by the views that others have of them and their actions towards them (Cooley, 1902). The meanings that an individual attributes to particular situations, however, can never fully be shared by others because individuals are unique and have exclusive sets of experiences (Blumer, 1969). People learn to share symbols and attribute meanings to actions and situations through language. In this context, meaning is conceived as something negotiated, constructed and continually reinterpreted rather than as something fixed or predetermined.

Blumer's stance also extended to methodological approaches to validate symbolic interactionist theory (Jones, 1994). He maintained that sociologists needed to adopt an anti-positivist attitude to understand the complexities of the social world; it is only by 'getting inside the defining process of the actor' that researchers can begin to appreciate attitudes, values and behaviours (Jones, 1994). These ideas were taken up by sociologists of the day; by Strauss in his description of staff and patient interactions in hospitals (Strauss, 1963), by Goffman in *Stigma* (Goffman, 1963) which explored how individuals understood and came to terms with particular disabilities and by Becker (Becker, 1963) in his presentation of deviant and normal behaviours. Becker (1963) argued that the meanings of such concepts are not immutable but are rather products of particular social frameworks that can change with time and under different circumstances. In the case of illness, therefore, it is not necessarily the existence of biological disease that is significant but how this factor is perceived, explained and responded to within society as these are the elements that determine in what ways people live their lives (Jones, 1994).

### **3.6 Labelling Theory**

One feature of symbolic interactionist research of which Becker played a part was in developing a theory about illness identities. Labelling theory as it was termed



describes the process of socially defined conditions, particularly deviant disorders, that are adopted or imposed on people. Labelling can arise through medical diagnoses or through the ways in which others; friends, colleagues, employers treat an individual. Such labels can result in a person being trapped in that identity. Horwitz has shown that the greater the social gap in terms of class and status between the labelled and labeller, the more difficult it is for the former to resist an illness stigma (Horwitz, 1977).

### 3.7 Agency

Interactionist theories (symbolic interactionism and labelling theory), however, have been widely criticised for largely avoiding the structural macro-sociological issues of class and power. Bourdieu argued for an analysis of social practices that link people and societies together (Bourdieu, 1993). He contends that whilst people are agenic beings there are nevertheless structures in society that constrain action. His central concept to explain the structural and action aspects of society is that of 'habitus'. Bourdieu uses this term to refer to the means by which individuals produce and reproduce social circumstances and enact certain forms of behaviour in ways that become almost automatic.

*'habitus... is close to what is suggested by the idea of habit while differing from it in one important respect. The habitus...that which one has acquired, but which has become durably incorporated in the body in the form of permanent dispositions...But then why not say habit? Habit is spontaneously regarded as repetitive, mechanical, automatic, reproductive rather than productive. I wanted to insist on the idea that the habitus is something powerfully generative...'* (Bourdieu, 1993 p. 86 )

The quotation here appears to suggest the idea that knowledge acquired from living in a particular culture or society to a large extent predisposes the choices made by individuals. Habitus is therefore conceived of as history embedded in people. Bourdieu does not deny a sense of human agency completely only that social circumstances are considered a powerful force that exert tremendous influence over

individual desire and self-will. These themes are discussed more fully in Chapter 7 with respect to respondent outcomes at the point of interview.

Other sociologists have also grappled with the concept of agency and structural constraints. Giddens' development of structuration theory constitutes an attempt to go beyond a divisional approach to this issue (Giddens, 1983; Giddens, 1984). In essence, his argument is that neither social structures nor social actions can exist independently of each other and therefore accounts which focus on one or the other are deficient. Social structures, in Giddens' view, should not be seen as purely constraining human action but also as enabling individuals to act as agents of social change. Critics of Giddens' work, however, suggest that his emphasis on agency must be seen in relative terms (Archer, 1995; Loyal and Barnes, 2001). The capacity of individuals to alter circumstances is dependent on opportunity, power, class as well as one's desire to make a difference.

### **3.8 Social Capital**

Social capital is also a concept that is closely allied to the structure and agency debate and is currently receiving attention from researchers and policy makers in the UK and USA in particular. Whilst it is a somewhat amorphous term, it is used primarily to refer to connections between individuals, social networks and the norms of reciprocity and trustworthiness that arise from them (Putnam, 2000). The basic premise of this theory is that interaction enables people to build communities, to commit to each other and in so doing provide a social embeddedness that allows citizens to resolve problems collectively more easily. According to Putnam (2000), there is considerable evidence that communities with a good stock of social capital are more likely to benefit from better health, higher educational achievement, lower crime figures, and better economic growth as a whole. Indeed, repairing and enhancing social capital is seen as the way forward in the UK to deal with difficult social issues. Yet, for Bourdieu & Wacquant,

activities like education and employment also operate through class-specific processes that are underpinned by economic investment (Bourdieu and Wacquant, 1992). As such, cultural groups and communities with high social capital have the means to exclude and subordinate others marginal to the mainstream and maintain the systematic inequalities that exist in contemporary society.

### **3.9 Postmodernism**

Postmodernism is not a theory as such but rather a movement or evolving understanding of the world towards greater diversity, fragmentation, conflict and pluralism. Its central thesis rests upon anti-foundationalism, the view *'that there is no firm ground or truth on which to base any system of beliefs, philosophical principles or research methodologies'* (MacDonald and Schreiber, 2001) p. 35). Postmodernist research seeks to deconstruct or tear apart the social world and rejects the notion of an absolute reality; knowledge is perceived as multiple, shifting, taking numerous forms and is constructed on an individual and collective basis.

### **3.10 Social Constructionism**

Social constructionism can be seen as one strand of postmodernist enquiry into meaning, subjectivity and the nature of social reality (Jones, 1994). This paradigm maintains that people construct their perceptions of the world, that no one perception is more valid or more truthful than any other and that these realities must be seen as polyvocal (Glesne, 2006). In general, constructivists reject scientific realism and objectivity, the idea that theories can chart, map or portray an accurate representation of the world (Schwandt, 1994). In contrast, knowledge is conceived simply as a set of social artifacts or a product of human cognitive ability.

### **3.11 The value and use of theory in the study**

Sociological theories offer different ways to explore the experience of chronic illness in society. This study was set in the context of how individuals and groups operate within the social world. The theories described above were used as sensitising concepts to assist analysis rather than to rigidly structure the research project from the outset. The meanings applied to events, experience and behaviour by participants were explored and interrogated as a first step to allow social processes within the topic area to emerge inductively. Social capital was identified as the overarching theoretical framework to explain the actions and outcomes of research participants after the empirical data had been analysed.

The postmodern emphasis on texts and a constructivist perspective acknowledges diversity and challenges the normative grounds on which we accept or reject 'truths' in society. Employment and disease status in the study, for example, were not necessarily mutually exclusive concepts and the expectation of most respondents was for well paid jobs with distinct promotional prospects. Symbolic interactionism situates individuals as creative and dynamic agents who create meaning from interaction with others and the activities they engage in. The respondents interviewed were active in self-care and defined themselves variously but rarely in terms of their illness or disability even though health workers and employers might see them in this light. Whilst agency was clearly a feature that permeated the lives of these young adults, it was not difficult to witness the effects of social constraints on individual actions. The patterns of difference on respondents in terms of class, gender and educational opportunities were very apparent in the research. Social policies in relation to education and employment are conceived by the current government as one way to increase social capital. Yet diversity in family life and labour market inequalities may militate against the capacity of local communities to act as mediating buffers to overcome structural disadvantage.

The impact of government investment in social capital and its long-term effect on young adults with illness in a multilayered society is, as yet, an unknown quantity.

### **3.12 Limitations of the study**

This study set out to explore the employment experiences of 30 young adults with different types of chronic illness. The project was located in a large conurbation of central Scotland. A larger project covering many sites could have selected respondents of different ages and with different conditions from a range of locations to yield a greater diversity of responses. As such my research must be seen as exploratory and small-scale. Studying a cohort of individuals over several years might reveal information about the career trajectories of those with child-onset disorders and the particular interplay between individual agency on the one hand and structural influences of educational policies and employment practices on the other. I have only explored the experiences of respondents from three disease groups. There are likely to be disease-specific characteristics that I have not encountered. Interviewing those who experience mental health problems may also have helped build knowledge in this area.

Researchers who take different theoretical perspectives might well generate new meanings and interpretations from the topic. Research, however, is always carried out against an ever-changing backdrop of social change and context. A range of theories create numerous approaches to view contemporary society and this can work to challenge taken for granted assumptions. Disability, for example, may be understood as a social construct of disabling experiences rather than as a normative model of physical or mental impairment (Thomas, 1999).

These were subjective accounts of young adults' experiences. Collecting and analysing data is a complex process and it is not self-evident that interviews represent unmediated access to individuals' thought processes. Some researchers (such as

(Atkinson, 1990; Silverman, 2000) believe that, because of this issue, narratives should be studied only as speech acts or as cultural stories although this point has also been avidly contested. In this study, employers' views were not sought. These might have provided a countervailing perspective to respondent accounts, particularly from the point of view of sick leave absences and workplace modernisation policies.

Analysis and interpretation depend upon the singular creative process between the researcher and the data. This process, however, is not fixed but develops and evolves as the research progresses. It can also be repeated and some researchers reanalyse their data from a different theoretical perspective from that used originally or employ secondary analytical methods on anonymised transcripts obtained from stored databases (such as the ESRC qualidata archive). Research outputs, then, are constructs that are generated by researchers themselves, they are not objects that gradually become discovered or revealed. As such, there can never simply be one response to a research question or just one method to investigate a topic. This study represents an attempt to study how young adults with chronic illness encountered and negotiated the various stages of the labour market and the circumstances that facilitated and obstructed that process.

### **3.13 Reflections on grounded theory as a method**

Atkinson considers research methods to be empty in themselves (Atkinson, 1991; Atkinson, 1995). By this statement, he makes the point that without theoretical perspectives to direct research, methods alone will not generate systematic and cumulative knowledge. One of the advantages of grounded theory is that it provides a framework from which to link data to theory. The continual cycling back and forth between constructing concepts and examining data, however, is a time-consuming process. It demands concentration at interviews, immersion in transcripts and the writing up of numerous fieldnotes and memos during the course of research. Abiding

by the various procedures of the method also involve lengthy periods of insecurity when connections between respondent experiences are not always apparent. Indeed, sometimes it demands a leap of faith to continue with the method in the hope that a framework for analysis will manifest itself at some point. In addition, the sheer volume of data is a daunting task although the use of a computer software package helps the problem of organising transcripts, identifying key quotations, and keeping memos and fieldwork notes all in one place.

Some of the theoretical concepts of grounded theory are difficult to grasp. The processes of theoretical sampling and data saturation, for example, appear potentially to be infinite. There is always the possibility that a further case will exhibit different properties from those interviewed so far so that the criterion to stop sampling might never be satisfied. As it was, my study was small, that of 30 individuals with only 10 of each condition being seen. It is possible because of this amount that the theory generated by the method might be conceived as *'thin, not well integrated, and (with) too many obvious unexplained exceptions'* (Glaser and Strauss, 1967 p. 254). Nevertheless, the interviews generated an extensive amount of data and across the dataset it was possible to identify recurring themes and to explore how socio-structural processes played out in the lives of these young adults.

### **3.14 Issues of quality**

Several authors and groups have published guidelines and advice for evaluating qualitative research (Greenhalgh and Taylor, 1997; Mays and Pope, 1995; Popay et al., 1998; Seale and Silverman, 1997). Others, however, have questioned the purpose of checklists and have wondered whether reducing research work to a list of technical procedures is overly prescriptive and does little in the end to confer rigour (Barbour, 2001; Sandelowski and Barroso, 2003). Silverman (2000), in particular, has been very critical of the quality claims made by some qualitative researchers. He maintains that



unless certain criteria such as validity and reliability can be assured, then field studies may suffer from anecdotalism. However, some of the common responses to improve rigour such as triangulation, the use of more than one method to address a research question, and respondent validation, cross checking of research findings with respondents, have been both simultaneously applauded and discounted by methodologists of the day.

From a postmodern perspective, issues of reliability, validity and generalisability are seen as modernist conceptions that correspond to a notion of an objective truth. In postmodernism, knowledge is conceived as a linguistic and social construction of reality so that concepts of 'quality' must be seen as relative to a specific theoretical framework or culture. The quest to uphold the scientific canons of validity and reliability are from this viewpoint unsustainable. Instead, an alternative notion of validation of findings has been suggested, that is an emphasis on providing arguments for the credibility of interpretations made (Kvale, 1995). As Barbour argues, issues of quality in qualitative inquiry need to be embedded into a broad understanding of qualitative research design and analysis itself and not stuck on as a badge of merit (Barbour, 2001).

There is no consensus, then, on definitive criteria to assess qualitative research even among interpretive researchers. However, most agree that one strategy to ensure confidence of findings is systematic and reflexive research design, data collection, analysis and interpretation (Greenhalgh and Taylor, 1997; Mays and Pope, 2000). Other approaches that seem to find favour include selecting a broad sample of respondents; providing detailed reports of original data to help readers make their own assessments; and thorough examination of transcripts to check for common and exceptional responses.

According to Glaser (1992) and Glaser and Strauss (1967), a well-constructed theory should meet four essential criteria: fit, work, relevance and modifiability. Fit refers to how well categories and properties relate to the data they represent. In other words, whether the grounded theory remains “faithful to the everyday realities of a substantive area” (Glaser & Strauss, 1967 p. 239). When categories are allowed to emerge and fit the data, the theory of the research should be a plausible explanation for what is happening to the phenomenon under study. In this project, categories were generated inductively from the data using the constant comparison technique and by building upon analytical aspects of memos. However, the prescribed method in grounded theory of generating a core category was not followed as a concept was not found that encompassed all components of the narrative. This research therefore was not a grounded theory study as such but was rather informed by the methods and procedures of grounded theory in terms of data collection, analysis and presentation.

Work or workability is concerned with the capacity of the grounded theory to explain the variations in the patterns of behaviour or reported actions of participants in the area of inquiry. It is not therefore possible to have workability without fit. The experiences of respondents in this study were multiple and the concept of social capital (described more fully in Chapter 7) provided an explanatory framework from which to investigate differences in action and employment outcomes of research participants at the point of interview. Factors affecting their beliefs and behaviours were rooted in their social contexts. Participant accounts of their personal circumstances generated insights into how decisions were made about health care, about education and about whether or not jobs were sought and/or maintained during adult years.

Relevance deals with the real concerns of research participants. It evokes “grab” (capturing attention) and should be of value and interest to study participants, practitioners and other researchers. This study reported the experiences of a sample of

young adults with long-term physical conditions and their management of health and experiences of employment. The relative lack of research in the area of employment-related issues would appear to indicate the worth of the study for practitioners and the research community given the emphasis on a work-focussed agenda in health and social care policy.

The term modifiability relates to the flexibility of the grounded theory to accommodate new data or changing situational realities within its storyline. Modifiability is considered important as it reflects the need for theory to maintain its relevance in a dynamic social world. Glaser (1992) argued that a grounded theory can never be absolutely right or wrong; it just has more or less fit, relevance, workability and modifiability and readers are asked to judge its quality according to these principles. As a theoretical framework, social capital allows individual experience to link with wider social processes and structural practices in society. Different experiences of people in other settings may throw up other findings but the concept of social capital is sufficiently broad to be capable of modification and the generation of new categories and properties when confronted with new data.

### **3.15 Conclusion**

Research necessarily involves making theoretical assumptions about the nature of the social world and about how it is to be investigated. This study is located within an interpretive paradigm which seeks to explore individual experiences and the meanings given to events in day-to-day lives. Grounded theory was chosen to examine how respondents manage employment whilst coping with difficulties brought about by illness. The next chapter sets out the construction of the research project undertaken, its origins and the interconnecting activities of fieldwork, collection of data and interpretation of findings. It charts the reflexive journey of the research process from

recruitment of respondents to engagement with individuals and the generation of thematic categories from narrative accounts. In so doing, it tries to provide a clear and transparent description of the method as it evolved over the course of the study so that evaluations of quality might be possible.

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## CHAPTER 4 - METHOD AS PROCESS: UNDERTAKING A RESEARCH STUDY

### 4.1 Reflexivity

The process of how research is undertaken has become almost as important as reporting the findings of studies. It is only relatively recently that social scientists have begun to think more critically about the effects of the researcher on all aspects of the research process. Finlay, for example, pointed out that, *'data produced by interviews are social constructs, created by the self-presentation of the respondent and whatever interactional cues have been given off by the interviewer about the acceptability or otherwise of the accounts being presented'* (Finlay, 2003) p. 5). This conceptualisation of research as a co-constituted product demands that researchers be aware of (some of) the influences they impose on research projects; from the questions they ask to the method(s) they employ and the ways in which they write up their studies.

How to reveal and integrate such reflexive practices into research, however, is a contested issue. The debate reflects different theoretical perspectives and has evolved alongside different paradigms of qualitative research. Finlay argues that reflexivity must be understood as a multifaceted concept with various dimensions and modes of practice (Finlay, 2003). Each method has strengths and weaknesses but in the end the goal should be for researchers to decide for themselves how best to exploit the reflexive potential of their own research projects (Finlay, 2003).

One approach to reflexivity is to examine the construction of the research project itself. This strategy makes explicit the stance, perspective and presence of the researcher during data collection as well as providing a methodological log of decisions made about research activities. Subjectivity is an inevitable part of the research process. Researchers bring with them their own motives, emotions, experiences and meanings to

fieldwork, data analysis and interpretation. My intention is to demonstrate how this study developed, from first beginnings through engaging with respondents to a final account of how themes emerged. In this way, the reflexive elements of the research are written into the process and interwoven throughout the sections of the chapter.

## **4.2 Origin of the research study**

The study developed whilst I was working as a Research Nurse on a Respiratory Unit at a teaching hospital in Edinburgh. I started the project partially informed by a nursing and biomedical perspective alongside a public health understanding of health inequalities. At that time, I was also interested in undertaking quality of life assessments alongside adopting inductive research methods to collect narrative accounts. Measuring how people feel and the values they place on various aspects of daily activity can be a powerful clinical tool. People with the same chronic illness can vary markedly in the problems they experience and the perceived impact of these problems in their everyday lives. The use of health related quality of life instruments helps practitioners understand the broader effects of illness and can be effective in distinguishing the relative benefits between different treatments and in comparing health profiles across conditions.

However, employment experiences among young adults with chronic illness do not readily lend themselves to predetermined variables. Using quality of life questionnaires would have told me very little about the day-to-day reality of respondents and how they managed symptoms of illness alongside working lives. For this reason, the study design changed from a mixed methods approach to one that was inductive and exploratory.

The original research questions (see p. 22) also changed somewhat over the course of the project. Whilst the topic area remained the same, I became less interested in what

factors facilitated or impeded employment opportunities and more intent on uncovering social processes underlying entry and maintenance of work for this group of people. As interviewing progressed, my comprehension of the implications of how young adults participated in the labour market grew. I realised that in order to understand the different employment outcomes of the sample at the point of interview, I needed to concentrate on the social context of individuals and the interplay between agency and structural forces operating in their lives. This not only demanded a more qualitative approach in terms of study design but also a broader, more process-oriented research aim. The main focus of the study became to examine the management of health care and the experiences of employment among young adults with a long-term condition.

### **4.3 Ethical issues and local access**

Researchers need to be ethical in the purpose as well as in the process of doing research. All research projects involving patients and health care staff require scrutiny and endorsement by a Research Ethics Committee. Approval was obtained for this study by Lothian Research Ethics Committee and a hospital NHS Trust provided written permission to allow me access to patient records (see Appendix). As my interest was primarily concerned with individual experience of health care and work issues, I did not consult the medical case notes of any person I interviewed.

Through informed consent, potential respondents were made aware that participation in the study was voluntary and that they could choose to withdraw consent at any point in the study. Assurance of anonymity was also provided. I used pseudonyms rather than numbering as a device to identify those who participated. The naming (however imaginary) of respondents helped me to preserve their sense of individuality although some personal identifiers were altered slightly to prevent any undue recognition of patients and health care professionals.



Transcripts of tape-recorded interviews were stored on my computer using pseudonyms as the identifying label. Field notes and the master list of names were kept in locked storage at home along with signed consent forms. When cited by respondents, the details of health care staff were also anonymised in transcripts and analysed with names substituted by alternative identifiers.

#### **4.4 Selection of respondents**

From the literature, I had noted that studies of chronic illness and work had mainly looked at participants from one disease group (Gillen et al., 1995; Milton et al., 2004; Packham and Hall, 2002) or had used self-reported measures of illness (Ireys et al., 1996). There was also a paucity of data on how young adults with chronic disease access employment and the strategies they adopt to maintain working lives. For these reasons, I concentrated on different forms of child-onset disorders. The hospital setting gave me access to respondents with specialist-diagnosed conditions who were likely to have had more severe symptoms than those managed solely in primary care.

I wanted to compare and contrast individual experience of employment among young adults with various child-onset disorders. I was interested in finding out about disease-specific factors affecting work as well as individual characteristics including gender, educational background, types of jobs undertaken and support available. Management of health care within these groups was also an important aspect of my research agenda.

The three disease areas of cystic fibrosis, juvenile chronic arthritis and diabetes Type 1 were chosen because they all shared certain features. These were: prevalence (cystic fibrosis, arthritis and diabetes are all common disorders among the UK population); child-onset of action (cystic fibrosis is a genetic disorder with physiological effects from birth, diagnoses of diabetes (Type 1) and juvenile idiopathic arthritis are frequently

made before age 16) and the episodic nature of the conditions. Validated quality of life questionnaires had also been developed for each of these three conditions which had been an original aim of the study. These diseases also vary in important criteria such as visibility of symptoms, course, impact and outcome on individuals. Using different clinical conditions also provided an opportunity to assess whether differences among the sample were due to disease characteristics or to other factors or even to a combination of them both.

The experience of young adults in particular was of interest. Employment studies of chronically ill or disabled populations have mainly addressed diseases of adult onset, such as multiple sclerosis (Brooks and Matson, 1982), chronic bronchitis (Williams, 1993), and cancer (Greenwald et al., 1989). Relatively little was known at the time about how young people with long-term conditions fared in the labour market. An age-range of between 20 to 30 years was therefore determined at the start of the study and a criterion was set of diagnosis before age 16.

All respondents were registered as either current or former patients of doctors working in three separate departments of one hospital in central Scotland. I attended hospital outpatient clinics (every other month for over 18 months) to invite diabetics who met the inclusion criteria to take part in the study. To help recruit those with cystic fibrosis, I used known contacts among specialist nurses to identify suitable participants. I met with a Consultant Rheumatologist on several occasions to obtain contact details of those with juvenile-onset arthritis who might be suitable for the research.

As a consequence, recruitment of respondents involved several strategies; telephone contacts, written invitation letters as well as face-to-face meetings with potential participants at outpatient clinics. It was, however, difficult to determine a precise response rate for the study. Several letters were returned to me by the post office with

addressee unknown on the envelopes. Hospital databases, even for current patient lists, were rather unreliable so I was unable to ascertain with any degree of confidence exactly how many people had actually received my letters but had ignored my request for interview. This problem may have been compounded by my interest in recruiting young adults who are in any event a very mobile group and change address at frequent intervals. In total, I received five outright refusals to take part in the study. Another rather frustrating issue was my inability to identify potential respondents who were not White and middle class. Whilst selecting other than White informants would have been difficult for the cystic fibrosis group (the disease is rare in other than Caucasian populations (NIH, 1990)), the recruitment pool for the other conditions also did not yield anyone who fulfilled the inclusion criteria for the study. This lack of ethnic mix was a limitation to the research. I did, however, endeavour to include respondents from a wide variety of social class backgrounds.

I found the use of pre-existing connections with hospital staff greatly facilitated my access to patients. On first approach all respondents were given at least one full day to decide whether or not they wanted to take part in the study. This combination of selection strategies helped to generate a wide range of respondents with differing backgrounds and experiences of work.

The exact number of respondents interviewed was determined in part by participant response but more crucially by the need to ensure that a variety of individuals took part across a range of workplaces and sectors. In addition, an equal number of respondents was required per group to allow for comparisons within and across disease areas. Sampling was therefore undertaken purposively. I interviewed thirty individuals in all; ten adults from each of the disease groups with an equal number of males and females per disorder. Being unemployed or never having worked were not set as exclusion criteria since data collected about schooling, perceptions of health, and perceived

barriers to obtaining and/or maintaining a job were expected to produce important information for the study.

Any person who was deemed unfit for interview by medical or nursing staff was not approached to take part. However, in practice such individuals were few in number. Two respondents who did volunteer to participate were slightly older than anticipated. As such, the age-range of those who were actually interviewed extended slightly from 20 - 30 years to 20 - 32 years.

#### **4.5 Stance as a nurse researcher**

Lofland and Lofland (1984) recommend expending time and effort to develop a carefully thought-out explanation or account of the proposed research when approaching respondents for interview. I presented myself as a nurse with no specialist knowledge of the respondents' conditions. I made it clear that I was there to find out about their experiences and feelings and not to provide advice on health or employment matters. These were in no ways 'therapeutic interviews'. My identity as a nurse, however, was both advantageous and inconvenient during the course of the study. On the positive side, it enabled me to gain a certain credibility among respondents; they were all familiar with nurses and could understand my approach to them, if not necessarily the reason(s) behind my study. What was less constructive was that my status may have prevented critical accounts being expressed about NHS care and more specifically about the nursing and/or the medical professions.

An extreme example of this potential shortcoming occurred when I interviewed one respondent on a hospital ward. For the most part, interviews were conducted at respondents' homes or in another mutually convenient location. In this instance, every time I had arranged to meet up, the individual had been admitted to a respiratory ward with a chest infection or some other exacerbation of his condition. After three failures,

we decided to conduct the interview in hospital shortly before his discharge. In fact, the respondent revealed that he spent nearly as much time on the ward as he did in his own home so I had few concerns about the choice of setting. One inadvertent consequence of this meeting, however, was that it was also held in the same department where I had worked up to 18 months previously. The staff knew me and the respondent, although I had never 'nursed' him, may have recognised me in that context.

Against all my expectations, the interview proved to be a challenge. Initially, the respondent was disparaging about the study and I began to wonder why he had seemed so keen to take part. For example, he could have easily provided an excuse not to have seen me at any time in the weeks prior to the meeting. His motivation to engage in discussion was never fully ascertained but his willingness to do so was ultimately rewarding. The extract below illustrates some of the confrontational tone of the encounter:

*Gary (CF): They (talking about his friends) don't make me feel different, they treat me as one of them. They understand that I am not going to walk 10 mile with them, so they don't put that on me, they don't expect nothing...*

*Helen: Does anyone make you feel different?*

*Gary (CF): Your staff*

*Helen: The staff here, you mean, not my staff*

*Gary (CF): Yeah, well, **they** (emphasis) like to remind you. You do not need to be reminded every bloody time you see them*

*Helen: In what way do you think they do that?*

*Gary (CF): Well every now and again they will say well, you know you are seriously ill, I know that, I do not need reminding...*

Whilst this was a difficult meeting, experiencing respondent antagonism was also instructive. It reminded me that consenting to an interview does not necessarily equate with polite, genial responses from a participant and moreover, that useful information could be gathered from the most unlikely informants. Gary's aggressive reaction was, in the end, extremely helpful to my later reflections on respondent perspectives of health care staff and in developing concepts around self-definition.

My dual presentation as both nurse and researcher in the study was for the most part easy to maintain. It was relatively simple to downplay my professional identity for I was unknown to all respondents (except perhaps to Gary). Whilst I acknowledged my status as a nurse, I tried to make it evident by careful phrasing of questions at interview that I was there to learn about respondents' conditions rather than to dispense clinical advice. This strategy appeared to have been successful on the whole. An excerpt below from a conversation held with one respondent with arthritis shows on the one hand her awareness of my nursing background and on the other, her willingness to provide detail about condition-specific treatment which may have been withheld if I was perceived as more expert in the field. It reinforces also that embarrassing incidents such as ones triggered by chronic disease were not suppressed by respondents during the course of interviews. Being a nurse and seen as accustomed to the effects of ill health may have facilitated this process of disclosure.

*Jackie (JIA): I got given splints for my hands but I hated wearing them.*

*Helen: Right, so did you bother wearing them?*

*Jackie (JIA): I have worn them a few times but I don't, I used to sit down and work them out (indicating how she did this) because they're not very comfortable at all. I don't know if you have seen them?*

*Helen: Not really*

*Jackie (JIA): They've got a great big metal spatula down the middle of them*

*Helen: Right*

*Jackie (JIA): When I was at high school they gave me a writing block because they said something about if you had your wrist at that angle it was better for you. I did get the mick taken out of me for that as they said it looked like a cat litter tray because it was plastic and at Christmas time they would say are you going sledging. I just used to carry it around the class...*

Comparing these two respondent perspectives side by side highlights some interesting issues about the acquisition of data. The setting, identity and stance of the researcher as well as the particular attributes of respondents can all influence and shape the type of information collected. An incidental meeting in hospital exposed the potentially tenuous nature of upholding dual identities in research environments. This is not to say that assuming a double role is unsustainable or that my status as both nurse and researcher in the study had been compromised by Gary's identification of me; only that accounts generated through being known professionally may be significantly different from those produced for unfamiliar interviewers. In addition, had I conducted the research among participants attending hospital outpatient clinics then the narratives obtained in that way would no doubt have reflected that chosen setting. For example, one could speculate that respondents in those circumstances might have focused more on medical issues or have been more restrained in comments made about health care management. The mode of entry, the approach of the interviewer and the specific location of fieldwork then both impacts on and become constitutive of the data themselves. Such factors form part of the theory of knowledge created by the research and it is precisely these contextual issues that limit the very generalisability of qualitative findings to other settings.

Denzin talks about the need for researchers to 'learn the language' of the group they study as they progress with their research (Denzin, 1989). In my project, respondents



from each of the long-term conditions had their own phrases they used for the symptoms and medication required for their illness. Often these were technical terms and my nursing background provided me with some appreciation of the meanings of these. I did not rely on this familiarity, however, but rather used the early interviews within each group to try to understand the interpretations respondents themselves applied to such phrases. I soon realised, for example, that my knowledge about diabetic management was out of date (epi-pens rather than orange needles were now the devices of the day) and drug advances had long been made in the treatment of rheumatoid arthritis since my experience of such matters.

One issue that remains open to debate is the idea of membership of the group under study. Some disabled activists (see (Morris, 1991) for example) have argued that able bodied researchers can never fully represent the experiences of disabled individuals such as themselves. Others take a different view (Lofland and Lofland, 1984; Seale, 1998; Silverman, 2000). In this research, there were important points of difference between myself as a researcher and the persons I interviewed during the course of the project. I do not have a chronic illness for a start nor did I pretend any such condition to the respondents in the study. I was also older than the sample by several years. Lofland and Lofland (1984) adopt a pragmatic approach to this question; they maintain that while identity barriers should be taken into account when planning research, these should not be over-emphasised. They go on to cite numerous examples of studies that contradict the notion that just because a researcher is not 'identical' to the persons being investigated then such research becomes impossible or more difficult to undertake.

It is also important to remember that individual accounts do not provide direct or unmediated access to life experiences (Thomas, 1999). Rather they represent storied versions or narratives through which people describe their world. In this study I was not concerned with the 'objective realities' of respondents; my interest lay instead in the

meanings and interpretations each held about their health status and experiences of work. The data therefore were treated as representational constructs as opposed to descriptions of factual life. This is not to say that respondents did not provide plausible accounts of their experiences nor that I regarded their responses as in any way rhetorical or fictional. Rather, the interviews gave me a route to understanding the kinds of socio-structural processes underlying work issues for young adults with chronic conditions. They allowed me to perceive the effects of discursive practices on respondents; how being diagnosed with an illness from childhood, for example, influenced their internal or subjective experiences.

#### **4.6 Data collection**

The in-depth interview was chosen as the main method for collecting data. I wanted to understand the kinds of meanings respondents constructed about how they managed their health in relation to working or non-working lives. This demanded an approach that allowed respondents the scope to talk in their own terms about the views they held and the actions they took and in ways that related to personal frameworks of belief. Such information would not have been so readily accessible by observing behaviours in a work setting, for example, or by requesting responses in a pre-set questionnaire.

Research interviews are social devices arranged by researchers to obtain respondent data about attitudes and experiences. Lofland and Lofland (1984) call them 'guided conversations' or conversations with a purpose. Hammersley and Atkinson (Hammersley and Atkinson, 1995)) and others (Jones, 2004, Silverman, 2000) argue that interviews are used to obtain detailed accounts of social phenomena that require context. Jones (2004, p. 259 ) reminds us, however, that an interview is a '*complicated, shifting social process occurring between two individual human beings...(as such) there cannot be definitive rules about the use of open-ended questions, leading and loaded questions, disagreements with respondents and so on*'.

Before interviewing, a topic guide or interview schedule was drawn up which consisted of a series of questions and probes around a number of themes (see Appendix). At the start of data collection, these included: respondent's state of health (both at time of interview and previously), treatment/management of condition, educational experiences, nature of past/present employment, work issues, benefits, social support and future prospects. As the interviews progressed, the schedule became more focused in certain areas, incorporating more questions on self-definition and the meanings of employment, for example, and less on social support networks.

#### 4.6.1 The process of interviewing

The interview guide was not adhered to completely. The format of questioning changed frequently and some areas of interest were expanded or contracted according to respondent replies and particular experiences. I found that some individuals were keen to launch straightaway into the types of jobs they had had whereas others required more prompting and needed a more chronological sequence before they divulged such data. It was important to stay alert at interview, listening not only to what was said but also how events or attitudes were expressed. Casual or offhand comments were sometimes extremely illuminating as Gary's remarks in the previous extract illustrate. I pursued areas with respondents which required further clarification, asking new questions where necessary (Lofland and Lofland, 1984) and integrating into discussions any developing theories or points picked up from previous interviews. In this way, I built up connections, tried to fill gaps and inconsistencies within the data (Glesne, 2006).

Inevitably the length of interviews varied. Typically, conversations lasted for about an hour but a few were only 45 minutes long and in one extreme case continued for nearly 2 1/2 hours. Individuals differed in how easy they found it to chat and speak freely and in how descriptive or eloquent they were at interview. The choice of location was

always left to respondents; most were conducted in individuals' own homes although two were held elsewhere, one in a tearoom and another at a workplace office. A hospital visit (as previously relayed) was made in a third case. These three young adults, all of whom still lived in their parental home, chose a more neutral environment for the interview. The reasons for this are likely to be manifold and can only be speculated upon but may include embarrassing or turbulent home lives and/or uncertainty over what was expected of them as respondents.

Interviewing respondents did not follow a consistent or uniform pattern. Not only did the format and content of encounters vary but so did research processes of data collection and other activities. There were times, for example, where transcription work and analysis predominated over fieldwork and other occasions when a number of interviews were conducted close together. Initially I tried to meet up with respondents from each of the three disease groups in order to develop consistent themes across the sample as a whole. However, my recruitment strategies were not always sufficiently flexible to allow me to explore emerging categories as they arose, such as gender differences, until much later in the study.

During the course of interviewing I became simultaneously more confident in my ability to collect useful data from respondents and more focused on the types of responses coming to light. I stuck less rigidly to my interview schedule as time went on and followed my hunches in seeking more depth and explanation around analytical concepts of interest. For instance, I used later interviews to enhance my understanding of how respondents defined themselves in relation to their own health status and those of others including perceived attitudes of health care staff. I also tried to concentrate on the meanings respondents attached to their work but this concept always proved somewhat elusive and difficult to unpick. A third category that required further elucidation was in determining when and in what circumstances respondents disclosed

their health status to employers. Disclosure emerged as an important concept in the study. It helped to clarify concepts of self-definition held by individuals and the meanings they assigned to their experiences of work. In this manner, analysis (theory building and saturating of categories) developed alongside data collection; there was no clear dividing line between the two processes.

I found that interviewing was a skill that could be developed and honed. Through making errors of judgement (I assumed quite wrongly, for example, that males would be less forthcoming at interview than females), I became more practised at it. Initially, I found it difficult to tolerate silences and tended to jump in with another question before respondents had sufficient time to think through or reflect on their responses. Later I resisted that temptation to a large extent.

Also, at first, I was too quick to switch off the cassette recorder at the 'end' of the interview so I missed, at least on tape, useful supplementary accounts given by respondents. Such data were obviously included in my write-up of interviews but were not available thereafter as authentic quotes. Whilst experienced researchers (such as (Denzin and Lincoln, 1994; Lofland and Lofland, 1984) warn against stopping recording prematurely, knowledge does not necessarily equate with actual behaviour in the field. In later interviews, when more familiar and self-assured in my ability to manage encounters, I tended to let tapes run on. This strategy was useful in obtaining additional information about an episode or theme and also allowed new concepts to emerge.

After switching off the tape of an early interview, for instance, a man with diabetes disclosed his feelings about having being sent a pamphlet by his university that described the support available for disabled students. Whilst he said that he endorsed inclusive practices for those with disabilities, he himself displayed personal affront at

being, as he believed, marked out as disabled by such targeted distribution of literature. These competing statements helped to focus my attention on the various definitions respondents applied both to themselves and those of others in terms of health status.

During the interviews, respondents on occasions appeared to test out their roles as research subjects. This approach took different forms and occurred at different stages in the conversations we had. When I first noted this happening, I included such episodes in analytical memos under my assigned term 'leaks'. I used this phrase purposely as it seemed to indicate some kind of break out from the traditional type of researched-researcher roles enacted in research contexts. By this description, I mean the 'conventional' interviewing format in which the interviewer adopts a hierarchical stance over the interviewee as described in classical survey research (Brunskell, 1998).

One form of 'leak' was in the questioning attitude adopted by some individuals concerning the selection of respondents for the study. For example, on first approach, a few people expressed the view that they were unlikely to be appropriate 'subjects' for this project. At first, I thought such responses merely denoted reluctance to take part but it also occurred when individuals seemed willing to arrange a time to meet up for interview. In spite of respondents receiving personal assurance and a letter of invitation as well as the information documents that explained the purpose of the study, some individuals continued to make assumptions about the type(s) of informants I needed to obtain useful data. They felt that I was interested only in people who had experienced problems in the workplace as a result of health status. My explanation of looking for ordinary individuals in order to explore common, frequently occurring issues was not always understood.

Another 'leak' that undermined so-called traditional roles was Gary's slip referring to my dual status as researcher and nurse. His response at interview no doubt reflected

his anger at the nursing profession. The importance of this statement, however, was a reminder of the nuanced relationship that always exists between interviewers and interviewees in practice. This relationship might be marked by power differentials or reflect a more closer connection as prescribed by many feminist researchers (Seale, 2004) but ultimately reveals the socially interactive nature of research encounters.

#### 4.6.2 Tape recording interviews and producing transcripts

All respondents were sent or given letters and information sheets about the study before consent to take part was assumed. It was always 24 hours and usually several days, even weeks in some cases, between receipt of these documents and the date arranged for the interview meeting. This gap enabled potential respondents time to consider whether they wanted to participate. Invitation letters explicitly included the issue of tape recording the interview discussion. I also sought verbal permission at the meeting with explanations given about confidentiality and who would be transcribing the tapes. No-one refused my request to tape-record the interview.

There is remarkably little discussion about the actual tools and techniques for recording interviews in qualitative research (Stockdale, 2003). Many methods texts (Fielding, 1993; Lofland and Lofland, 1984) focus on the debate between various options; that of recording interviews or of note-taking (or both) and whether full (verbatim) or selective transcriptions are necessary. Patton among others (Atkinson, 1991; Lofland and Lofland, 1984; Silverman, 2000) recommends recording whenever possible insisting that, *'as a good hammer is essential to carpentry, a good tape recorder is indispensable to fine fieldwork'* (Patton, 2002) p. 380. He goes on to cite an example of transcribers at one university who estimated that twenty per cent of the tapes given to them were so badly recorded as to be impossible to transcribe accurately or at all. Most researchers (Lofland and Lofland, 1984; Patton, 2002; Silverman, 2000) also advocate full verbatim transcriptions to exploit all possible analytical uses.



Digital audio technology now provides potential benefits for the quality of recorded research interviews. Decisions made about recording equipment can play a central role in gathering usable and suitable research data. In the early stages of my study, I considered buying a minidisc recorder but was put off by questions about the robustness of such systems. Stockdale (2003), for example, maintains that minidisk recorders are more complicated to use than cassette recorders and a bad disc or shock during recording can cause loss of an entire data file. For these reasons, in addition to the cost of hard drive and solid state recorders, I chose the traditional analogue format.

I initially used a Sony TCM 500DV tape recorder with an attachable tie pin microphone that I placed flat on a table or chair as close to a respondent as possible. When transcribing, however, it became clear that softly spoken words were indistinct or off-mike and some sections were lost altogether. I managed to retrieve certain responses using notes from my interviews but not all were recoverable. I quickly discovered that the high sensitivity button on the recorder not only picked up the voice of a respondent but also any other ambient noises prevailing at the time. I learnt therefore to use this feature selectively. It was also important to ensure that the voice activating switch on the cassette recorder was turned off during interviewing as this further decreased audibility.

After struggling to record the interviews of five respondents using these tools, I decided to switch to a condenser unidirectional microphone (Sony ECM – Z60) which produced much better sound quality. Around this time I appointed an audiotypist to help with transcription work. I was finding that too much of my time was spent transcribing interviews at the expense of other research processes. There was also too big a gap between interviewing a particular respondent and having a transcript of the encounter to study. Some commentators (Tilley and Powick, 2002) advise caution when hiring individuals to transcribe tapes of research interviews. However, time is also a

valuable resource. Silverman points out that the search for a 'perfect transcript' is illusory and time consuming and the aim is rather to arrive at a document that is adequate for the task at hand (Silverman, 2000).

To transcribe recordings, I used a Sanyo Memo-scriber TRC-8080 with an attachable foot pedal that had a delay rewind system. In the end, I transcribed about half the tapes myself and listened, amended and added to the other fifteen. I realised quite soon that whilst generally accurate, the audiotypist had a tendency to 'tidy up' repetitions and false starts that occurred in the interviews and was often reluctant to transcribe speech in its vernacular form. She also found specific vocabulary about respondents' conditions difficult to decipher. I found that correcting transcripts was an iterative process that entailed listening and re-listening to tapes and adding to and deleting bits of text in order to achieve a reasonably accurate account of each interview.

In order to clarify meaning and make transcripts more readable, I put in commas to indicate pauses in speech and full stops to signal silences or a change in topic. I also included tones of voice where appropriate (such as sarcastic), body language (such as gesturing) or particular characteristics (such as laughter) when they occurred. Silverman (1994) reminds researchers that the preparation of transcripts depends on the purpose of the research. Since I was concerned with exploring respondent experience of health and employment in order to be able to categorise and explain recurring themes, I did not attempt to count pauses or identify particular speech patterns. My interest primarily was in understanding the feelings and views respondents seemed to hold and the motivations they ascribed to their actions. Transcriptions allowed me to re-remember each interview encounter and to compare my ideas about what seemed to be important with what actually was said at the time. It also helped the flow of conversation and enabled me to listen more intently to respondents.

#### 4.6.3 Fieldnotes, descriptions and analytical memos

Fieldnotes were written immediately after each interview. These covered both analytical and descriptive comments relating to contextual factors such as place of discussion, personal impressions, order of events and conceptual ideas arising from the data. Descriptions of each interview were also made. Denzin advocates the use of 'thick description' to generate accounts of stories respondents convey in research settings (Denzin, 1989). This technique aims to identify the most significant events of the 'interactional experience' and the meanings and interpretations attributed to personal behaviour. My descriptions focused on the content of encounters and provided a resume of the issues covered within each discussion. They were used both as a reminder of the interview and as a basis for comparing and contrasting respondent experience.

Alongside these descriptive summaries, I produced analytical memos. These contained developing ideas about the data which progressed in complexity as time went on from observational notes to more complex reflections on meanings and explanations of accounts (Strauss and Corbin, 1990). In this way, recurring themes were identified across and within groups and any gaps in the data were logged and fed back into the interview schedule for future use. For instance, after completing 5 or 6 interviews, I realised that I had collected little data on the process of decision-making around work issues. This perception triggered a series of questions about when and in what contexts individuals first considered jobs and whether health status affected choices made about employment.

In later stages of interviewing, memos were used more conceptually in order to amend, support, clarify, extend or negate previous theories about the data (Strauss and Corbin, 1990). In this way, they provided a 'fund' or storehouse of analytical ideas that could be sorted, ordered and classified according to need (Strauss and Corbin, 1990). This

function was particularly successful in making sense of the circumstances surrounding disclosure of illness. Reasons for divulging details about health problems at work or during job interviews emerged as complex and dependent on context, timing, and the trade offs between perceived advantages and shortcomings. This theme would have been more difficult to analyse if conditions influencing disclosure and non-disclosure had not been documented in memos throughout the study.

#### **4.7 Data management**

Data overload can be a serious problem in qualitative research (Lee and Fielding, 1995; Miles and Huberman, 1984; Seale, 2000). Even small projects generate huge amounts of textual information and keeping track of emerging ideas and theoretical concepts imposes great demands on researchers' organisational skills (Kelle, 1995). One way of storing and managing data is by the use of computer software designed specifically to deal with word processed material. There are a number of computer-assisted qualitative data analysis systems (CAQDAS) available although this term is somewhat misleading as programmes cannot analyse the meaning of texts themselves; that is an interpretive act. Their strength instead lies in their sort and retrieval functions. These facilities enable transcripts to be coded into text segments which can then be filed and revisited when necessary.

Grounded theory has influenced the development of CAQDAS. One reason for this is that, at the level of analysing data at least, grounded theory provides a reasonably detailed description (albeit at times confusing) of the operations required in qualitative research. An additional advantage of CAQDAS is that it can help researchers demonstrate that the conclusions they reach are based on rigorous analysis (Seale, 2000). For large datasets, this can be undertaken by counting the number of times things are said or events occur but it can also be enhanced by ensuring that a reliable coding system is applied (Kelle and Laurie, 1995). CAQDAS packages identify patterns

in data more quickly than manual methods (Seale, 2000) and assist in the process of searching for commonalities, differences, themes and structures.

Although CAQDAS has been gaining in popularity among social scientists since the 1980s, some researchers have been reluctant to engage with computer software to assist in data management. This reaction in part represents a kind of technological conservatism against the dominant orthodoxy, that of quantitative methods which use computerised statistical programmes for analysis (Seale, 2000). Others question the over-reliance on the code and retrieve approach of CAQDAS that is seen as detrimental to textual interpretation. Denzin and Lincoln, exponents of this critique, extend the argument further to include concerns about reification of outputs over process issues (Denzin and Lincoln, 1994).

An additional limitation of grounded theory or any other method that breaks up text into categories, is the potential danger for data fragmentation. Textual segments can become divorced from context as the meanings of passages can depend on relationships to wider chunks of data and/or the order of events in a narrative. NVivo, the package I used to manage information, resolves this problem in several ways. It allows links to be created between memos and codes, codes and codes (termed nodes in NVivo) and codes and full transcripts of data. I tended to use the latter strategy in my analysis to ensure that the fragments of text used to support conclusions or arguments were justifiable in context and fully grounded in the accounts provided at interview.

#### **4.8 Developing analysis**

Other commentators (such as (Lofland and Lofland, 1984) and (Marshall and Rossman, 1989) take the view that qualitative research has historically adopted the standpoint of the 'underdog' and should reflect the experiences and perceptions of ordinary people.

In so doing, the trick is to avoid romanticising respondent accounts and instead view them as part of a process through which interpretation is negotiated.

In NVivo, it was an easy task to assign labels to data, change codes and mark same text segments in different ways. Analytical memos produced during the course of research, were able to be stored, amended and retrieved at will to aid concept development. Memos were treated either as individual documents (I mainly reserved memos of this status for early thinking about data) or linked to codes where attributes were sometimes attached to signify referential properties. Descriptive terms were allocated to broad categories of data in my project. Generating a consistent coding scheme was made easier by this method; there was less likelihood of confusing the type(s) of information chosen for an assigned label and it ensured that categories were populated with all relevant segments from the dataset.

In order to interrogate each category and its component links (memos, fieldnotes, other data codes), I compiled a series of questions around a theme. These enabled me not only to check out *a priori* and emerging hunches but also helped me to challenge any assumptions I may have made about the data up until then. For example, under one category or node tagged as 'How to get employment', the following general lines of inquiry were used at the outset to build up its properties and dimensions.

- Does disease state alter decision-making about employment?
- Is employment seen as a worthwhile enterprise compared to benefits?
- Are there gender or disease status differences in respondent attitudes towards seeking work?
- Are employment decisions made early or after school/higher education?
- Does career advice influence employment choices made?
- What strategies were used to obtain work?

- Why were these particular ones used?

These initial questions around a category were not exhaustive and indeed often stimulated others when the dataset was explored in depth. Their purpose was rather to help encourage theoretical thought and served to frame my analysis of the data. Glaser and Strauss (1967) and Strauss and Corbin (1990) refer to the ability to see analytic depth in data as 'theoretical sensitivity' and suggest the use of such questioning as an effective tool with which to interrogate transcripts and other accompanying documentation. Sometimes this technique failed to resolve questions I had posed and I was required to take another look at the node abstracts and/or re-read transcripts again. Lines of inquiry in these cases were modified or changed completely to reflect new insights.

I retrieved data segments for each category from the dataset and checked out questions by comparing disease group against disease group, females against males, and case against case for individual strands of analysis. This constant comparative method was time-consuming and iterative; it entailed an alternating, to and froing between text fragments and full transcripts until all questions had been answered. In this way, data analysis developed inductively; categories were considered complete only when context, properties and conditions had been determined.

In most cases, patterns of agreement emerged between respondents so underlying themes in the data could be drawn out and described. However, it was also important to detect differences in attitudes and behaviour across the dataset. Deviant case analysis or divergence of opinion was fruitful in clarifying the conditional aspects of categories, for example, when looking at dichotomous factors such as gender and working/not working and in more complex situations such as the circumstances influencing whether individuals considered themselves 'disabled'. By this technique,



interpretations and theories about the data had to be frequently modified or refined to fit all cases across the sample.

Categories in the data reflect descriptions supplied by respondents (such as how episodes of illness were managed) and theoretical concepts constructed as a result of those data (such as the impact of illness in childhood) in order to link them with other themes and published studies. For example, it was clear that entry into work was affected by respondents' adopted policy on whether to reveal or conceal health status at interview and throughout employment. This type of information was categorised using conceptual tags commonly applied by other research teams (such as disclosure, self-esteem and the use of the term 'work adjustments' cited by the UK Disability Discrimination Act and various commentators in the literature). This strategy, commonly used in grounded theory, enables theory to develop and be built upon by others although it can also be deployed to confirm or refute existing knowledge about a topic.

A choice was made to provide a biographical layout to analysis. It became evident early in the study that issues about work for respondents were interconnected with school attendance, the effects of illness in childhood and the consequences of a diagnostic label on available job options. The cumulative effect of these factors meant that logically educational experiences should precede any findings about employment rather than vice versa. Deciding on this approach to analysis reduced the potential to construct a more conceptual or theoretical presentation whereby categories can be chosen for their ability to subsume common patterns (Charmaz, 1990). The notion of agency versus structure in my research, for example, would have linked to codes around proactive self-care management of health as well as those about attitudes and actions applied to work-related themes. This manner of illustrating data, however, might have compromised or confused the temporal aspects of the analysis. A core

category was not created in this study for precisely this reason and in fact, the research findings were broken down into two overarching sections, management of illness and experience of employment. Concepts such as labelling, agency and identity were important theoretically and were grounded in instances in the data but have been interwoven amid the biographical constructs of the analysis.

#### **4.9 Writing analysis**

There are various conventions for writing up qualitative research findings. Strauss and Corbin (1990) recommend writing conceptually, making the most of developing a core theme and keeping any description as secondary. Others assume a less prescriptive approach (Lofland and Lofland, 1984; Seale, 2004; Silverman, 2000). Still more advocate a complete turnaround in the 'traditional methods' of reporting research. This is Denzin's take (from 1988) on how fieldwork in the social sciences will evolve:

*'...Post-Geertzian anthropologists are now writing on the politics and poetics of ethnography. They are taking seriously the question, 'how do we write culture?' They are proposing that postmodern ethnography can no longer follow the guidelines of positivist social science. Gone are words like theory, hypothesis, concept, indicator, coding scheme, sampling, validity and reliability. In their place comes a new language; readerly texts, modes of discourse, cultural poetics, deconstruction, interpretation, domination, the authority of the text, the author's voice, feminism, genre, grammatology, hermeneutics, inscription, master narrative, narrative structures, otherness, postmodernism, redemptive, ethnography, semiotics, subversion, textuality, tropes.'* (Denzin, 1988) p. 432 )

The text then, be it qualitative research or rhetorical discourse (Atkinson argues that research is inherently rhetorical (Atkinson, 1990)) invites different means of representation. Narratives or data analyses can be written up as stories-in-progress or as tantalising poetic dramas where no one definitive version is offered. Whilst this is one way of subverting the 'monster of reflexivity' as MacMillan terms it (MacMillan, 2003), (when the process of doing research becomes the central topic under investigation), such accounts can also become 'postmodern tales' abnegating any moral or authorial responsibility for taking a stance. Whilst there may be no singular report

of qualitative research that is more 'valid' than another, equally interpretations should not be proof against criticism. Conclusions drawn about fieldwork may be unjustified by the data or the quality of the evidence presented.

Seale advocates a return to a more authoritative convention of writing research connected to reflexive self-awareness (Seale, 1999). This perspective entails reinstating the researcher as author of the text and making explicit the processes involved in evidence gathering and data display. In this project, quotations were deliberately shown as the focus of the research. Rather than providing a 'high level' analysis that overrides the prominence of transcript extracts, I chose to expose the empirical bases on which interpretations were made. Extracts of text were therefore selected for their representativeness and as evidence of the explanations given in the analysis. The presentation of quotations in this way grounds the data more fully and makes decision-making about claims of conceptual meaning more transparent. In addition, peppering the analysis with data brings some simplicity to the complex process of theoretical writing and creates thereby a coherent structure to the text.

The research schedule was necessarily rather loose to provide the flexibility required to follow issues and hunches arising from the discussions through in more depth. As a consequence some questions were not always directly asked of every respondent either because the line of questioning only began in later interviews (such as the process of decision-making around work issues) or because other issues were given a higher priority by a particular individual. In order to provide some indication of the frequency with which certain views were expressed, I have used terms such as 'few' to specify comments made by between three to five respondents, 'some' or 'several' to denote responses made by six to nine of the sample and 'the majority' to point out twenty or more common, separate replies. Occasionally more precise descriptors have

been employed such as 'a third', 'a half' or 'almost all' to provide greater clarity about the convergence or divergence of views.

The findings of the research have been written sequentially. They echo the chronological order of events occurring in the lives of respondents from initial timing of diagnosis and effects on school life proceeding to management of condition, through choices made over employment and work issues to arrive at future concerns. This device provides a 'natural' logic to the narrative. 'Factual' information has been combined with strands of analyses to locate the incidents the individuals convey, such as employment experiences, and the number who drew incapacity benefit or other related disability-benefit. In this way, data have been contextualised; reported activities juxtapose with interpretation to impart situational validity to the analysis.

Interview data in this report have been treated mainly as a resource (Seale, 1998). This approach seeks to discover facts about the social worlds that respondents experience. Whilst people's accounts do not represent literal depictions of reality, they can nevertheless provide a means of exposing the socio-structural processes at play in given settings. I set out to explore the factors facilitating and impeding working lives among young adults with chronic illness. Examining their narratives has helped reveal the types of actions and incidents others with similar conditions may face. The sample is small but the depth and breadth of information collected about illness and employment encourages insights into how young people with child-onset disease fare as they approach and begin to experience the labour market as adults.

#### **4.10 Conclusion**

An explicit part of data production and analysis in qualitative research relies on the reflexive engagement with respondents. The role that a researcher adopts and the theory of the method undertaken shapes the way research is conducted and how

outcomes are reported. The next two chapters document the findings of the research project and chart the impact experienced by individuals in managing effects of illness and engaging with employment issues.

## **CHAPTER 5: YOUNG ADULTS' EXPERIENCES OF LONG-TERM CHRONIC ILLNESS**

### **5.1 Introduction**

A heterogeneous mix of young adults with cystic fibrosis, arthritis and diabetes Type 1 participated in the study (see Table 2 for profile of sample pp. 130-131). Thirty respondents were interviewed in total, ten from each of the disease groups with gender represented equally across the sample. All gave informed, written consent for the conversations to be tape-recorded. The level of disease severity differed within and between groups and no attempt was made to classify degree of illness by the use of clinical measures. Diagnosis of condition in all cases had been made by medical specialists (hospital consultants) and respondents still attended (or had previously attended) hospital outpatient clinics for continued treatment and assessment of their chronic illness.

The accounts of respondents and data analysis of their interviews have been spilt into two chapters, this one on experiences and management of chronic illness and the following one on experiences of employment. Each chapter deals in turn with the dual focus of the study, the impact of a long-term illness and its effect on employment outcomes for young adults. The themes follow a chronological course because early experience in formative years across the sample appeared significant in influencing future outcomes and behaviours. The ways in which illness was experienced by participants affected their management of condition, their sense of self and their attitudes towards formal health care services. Hence the description of diagnosis and childhood experiences precedes analysis of issues associated with self-esteem, health status and how others respond to them on an individual and societal basis. Each section within the chapter therefore provides data in a cumulative manner to reinforce

the commonality of experience in terms of how impairments were regarded, managed and controlled by the young adults in the sample.

This chapter specifically looks at how the respondents perceived and dealt with their conditions. It examines the reported effects of child-onset disease on school lives including educational attainment and the social and psychological impact on self-image and self-esteem. Illness was experienced dynamically with individuals taking an independent stance towards care and treatment. Secondary health services came in for criticism and some of the concerns expressed by these respondents are reported and discussed.

## **5.2 The impact of diagnosis**

The respondents interviewed had all been diagnosed with their respective condition before the age of fourteen. All but one of the sample with cystic fibrosis had known of their disease since infancy. The other, with a life-long bothersome cough and having had a sibling with CF, was eventually diagnosed in adolescence aged about thirteen. For those identified as having juvenile-onset arthritis and diabetes, the time of diagnosis occurred variously between 2 and 14 years.

Diagnosis itself was usually a surprise, a bolt out of the blue for children and parents alike which typically required a period of adaptation before normality, albeit of a different kind, resumed. Those with diabetes generally presented with classic symptoms of weight loss over some weeks and excessive thirst that required drinking large amounts of fluids. In most cases, diagnosis and treatment were rapid. Only in one instance, did a respondent spend more than two weeks in hospital after initial confirmation of the condition. Memories of the circumstances leading up to



hospitalisation were still acute for these individuals even after several years had passed.

*'It sticks in my mind, the main thing I remember is that I was really thirsty all the time and I was sitting in the class at school thinking, oh God I have got to get a drink soon. I lost a lot of weight but I was quite skinny then anyway, so I didn't really notice that I had lost weight but I just started to feel really weak and dizzy when I turned my head and then just going to the toilet all the time through the night and that.'* Cara (D)

*'...then they got the blood test result back in the afternoon and I was shipped into the hospital where I was for about a week. But it was actually strange because they managed to get my blood sugar level down quite quickly within 24 hours it was at 20 which felt amazing for me. But I did not feel ill after that. I woke and went to the loo and did not feel so lethargic so it was a bizarre experience being ill and actually not having any illness or so it seemed.'* Hugh (D)

By way of contrast, those with cystic fibrosis had no recall at all of a life prior to their condition. Even Ursula, who was not diagnosed until she was thirteen, was always susceptible to chest infections and frequently required time off sick for childhood illnesses.

*'It manifested itself a bit more when I started to go to school and although I did not really, I suppose I did have quite a bit of time off school but I think that was more that I could wrap mum round my little finger when I did not want to go. I would say I feel a bit coughie or I've got a cold. Obviously when I got a cold it did manifest itself stronger than for anyone else and I had measles and things like that which is the other thing which they thought could have affected the lungs.'* Ursula (CF)



<b>Christopher</b>	D	22	Male	Scottish	Living with parents	State	Standard grades	Warehouseman
<b>Colin</b>	D	27	Male	Scottish	Living alone	State	Higher grades	Own business
<b>Hugh</b>	D	21	Male	Scottish	Living with mum	Private	Higher grades	Student
<b>Oliver</b>	D	26	Male	Scottish	Living with parents	State	Standard grades	Steelworker
<b>Peter</b>	D	23	Male	Scottish	Living with parents	State	Standard grades	Student
<b>Bryony</b>	JIA	28	Female	Scottish	Living alone	State	Highers/ SVQ	Veterinary nurse
<b>Jackie</b>	JIA	23	Female	Scottish	Living with parents	State	Degree	Shop assistant
<b>Kate</b>	JIA	22	Female	Scottish	Living alone	Private	Standard grades	After school club carer
<b>Sarah</b>	JIA	32	Female	Irish	Living with spouse/partner	State	Degree	University Administrator
<b>Xanthe</b>	JIA	28	Female	Scottish	Living with parents	State	Standard grades	Out of work
<b>Andrew</b>	JIA	28	Male	Scottish	Living with parents	State	Higher grades	Restaurant worker
<b>Iain</b>	JIA	21	Male	Scottish	Living with spouse/partner	State	Higher grades	Customer service representative
<b>Theo</b>	JIA	26	Male	Scottish	Living alone	State	Standard grades	HGV mechanic
<b>Will</b>	JIA	22	Male	Scottish	Living with parents	State	Standard grades	Joiner
<b>Zavier</b>	JIA	21	Male	Scottish	Living with parents	Private	Higher grades	Student

For respondents with arthritis, diagnosis was rarely a straightforward or one-off event. Individuals typically described a process of protracted consultation with various primary care and specialist staff before confirmation of disorder was finally secured. In fact, some children were initially treated for other complaints prior to the final diagnosis.

*I was out playing with my pals and doing the usual kids stuff doing handstands. I came in the next day and my knee was swollen up, I could not actually see my kneecap. Went to the doctors and he said I don't know what it is, we'll send you to the sick kids. Sick kids said well it could be a ligament or something in your knee. This went on for a while then they did a blood test and said it was arthritis.' Jackie (JIA)*

*'I was about 5½ or so when it first came, I had a really swollen knee and originally my doctor just thought it was just fluid on the knee and took it out himself on a home visit, just stuck a needle in and took out all the fluid. Ugh, that put me off needles for a good few years. I actually went round to about 3 hospitals and they took samples from my knee and stuff because they could not work out what it was.' Iain (JIA)*

A lengthy time-gap between symptoms and diagnosis is commonplace in arthritis. However, current guidelines recommend aggressive treatment at the outset, including the use of disease modifying drugs in children and young adults to maximise long-term outcomes (Luqmani, 2006). The lack of a clear-cut, diagnostic test complicates the issue of medication and adds to the uncertainty at presentation of how to deal with the effects of pain, fatigue, joint swelling and weight loss that may occur.

Learning to cope with a diagnosis of chronic illness seemed to involve respondents making use of a variety of strategies including in many cases a request by parents for information and support from patient organisations. At interview, however, the majority of young adults seemed to find it difficult to remember with any degree of clarity what their lives had been like before the onset of illness. Indeed, for many, their condition had become indistinguishable from themselves as a person. Letting go of childhood dreams was also part of the reality of growing up with a long-term condition as is demonstrated in the following section.

### 5.3 Growing up with illness and effects on educational attainment

About half of respondents (both males and females) reported little or no effects from their chronic illness at school. These individuals insisted that they were not treated any differently from peers and they seemed unwilling to blame any lack of educational success on their diagnosis.

*'I think I did all right at school but I could have done better but that was just personal, not pushing myself, nothing to do with the diabetes.'* Anna (D)

*'There was no exemption, there was no mollycoddling or wrapping in cotton wool. You got treated exactly the same way as everybody else. I think having been brought up in that environment where you can't duck out and say oh terribly sorry I have CF, you just learn to get on with life.'* Quinn (CF)

*'I am not very physical at the best of times. I think a lot of that is just laziness not my arthritis. I can't remember it stopping me doing anything.'* Bryony (JIA)

Males in the sample were much more likely than females to complain about being unable to participate fully in sport activities as a result of their condition. For boys of school age particularly, sport appeared to have played an important function; friendships had formed around football and rugby teams and being 'sporty' earned a degree of kudos amongst peers. The impact of illness had the potential to upset childhood desires of becoming a professional sportsman but ambitions such as these were usually short-lived.

*'At primary I just ignored the doctors and went away and played football, all my mates played, the doctors advised if you feel you can do it, do it but they did say try not to do it for long periods. And if you feel tired stop. But none of that really kicked in until I was at secondary school and after that I sort of knew myself that I couldn't do the stuff anymore. I mean I tried to take PE standard grade because I wanted to do it but that's when they told me officially I shouldn't do it because it would be too much. That was hard at the time obviously being a school kid wanting to do my own thing I didn't like it especially with my mates and stuff and all my friends were taking it and I wasn't. I did argue and moan a bit at the time but the same time I also knew that I've been told things because of my illness so it was nothing new.'* Iain (JIA)

*'I suppose theoretically if I was to say I was not diabetic it would be very difficult to say where I would be at but when I left school I was very keen on rugby and then I was*

*playing for various district teams and there could have been a career for me within rugby. Rugby was not professional until 2 years after I left school. I suppose I say that now if I'd not been diabetic I would have pursued a career in a sport but then that's pie in the sky.'*  
Colin (D)

About ten respondents recalled being at least partially affected by their diagnosis at school age. Apart from sport activities, the most other commonly reported problems were ill health and being seen or treated differently from peers. Even missing a few weeks of school could have disruptive consequences although the intervention of teachers had the potential to overcome educational disadvantage triggered through absence.

*'I was actually really, really good at school. I was quite smart from young but I think as well I spent so much time in hospital I did a lot of reading, it basically meant that I was always been top of my class basically even although I was ill. I did really well in my exams. School has never really been a problem for me at all...I had teachers who knew all about it so they were there when it all kicked off so I had teachers coming in to see me and giving me work most of the time when I was in for longer than a week or two. But most of the time I would be ahead anyway when I was off so everyone else had caught up with me when I got back.'* Iain (JIA)

*'My primary schooling in particular from the age of about 4 until about 11, 12 was hugely interrupted. Some years it wasn't too bad but other years I probably missed about 3 months in the year and I'm useless at grammar, I think I missed that entirely, I'm not joking I really did miss it, and certain subjects I'm probably weaker on'* Sarah (JIA)

Some respondents spoke of occasions when they were teased or bullied because of their condition. Most times it appeared that these were not serious events and pupils were able to resist the worst excesses of bad behaviour by peers.

*'Aye you would get teased and that but you would give it back. That's no problem for me I can give it out as good as I get.'* Oliver (D)

*'I did not like primary school because as I said I used to sit on my own. High school was a bit much the same but after primary school I knew people could be nasty so I thought well I've not going to take it when I go to high school.'* Jackie (JIA)

*'When you are first diagnosed I think that's when you have a problem with it. It's quite a young age to be diagnosed with something where you have to take on, accept responsibility. I wouldnae monitor my blood sugar often but then there was a complication in it because*

*now when I want to take my blood sugar I just stop and take it and inject, when you're at school and you're in lessons and you're learning you cannae do that so I think it's much more difficult for youngsters. There is a lot of stigma attached to it. When I was first diabetic you had the old syringe, you'd get called a junkie and you have to take that, I could imagine that could be hard for some people.'* Christopher (D)

Living with a chronic illness seemed to evoke intense emotional responses for some at a young age. Circumstances were recalled whereby the feeling of being viewed as different in some way had been hurtful and individuals involved in this activity were often quickly denounced. This type of reaction was particularly seen amongst females in the sample. Whilst friends' misconceptions about health status tended to be accepted, respondents were far less forgiving of those (usually teachers or other adults) who made, or had attempted to make, unsolicited concessions on one's behalf.

*'And school camp, teachers would try to stop me doing activities...they did make me sort of sit back or something on occasions...They really didn't know what was going on and they were frightened that I wouldnae. I was quite content to give anything a bash and fall over or whatever.'* Anna (D)

*'At primary school they (teachers) knew and they tried to wrap me up in cotton wool so when I went to secondary I didn't tell anybody because I didn't like it...they made it obvious to other kids that there was something although I didn't feel any different to any other kids so then you got questions.'* Ruth (CF)

*'The lecturers at College, they'll stop and stuff and say to me do you want a break then and I say, no I'm fine and so yeah there is times when people feel as if they're doing you a favour by doing stuff and you're like, you're not doing me a favour.'* Cara (D)

These female respondents regarded the conduct of such authority figures (teachers, lecturers) as essentially paternalistic by ignoring their right as individuals to make decisions (and mistakes) for themselves. In so doing, they felt as if they had been singled out, marked as different and robbed of individual determinism. Equally, others (particularly those with diabetes) recounted situations where the actions of adults, perhaps unthinkingly, had labelled or stigmatised them because of health status.



*'It was silly little things. When you think about it now it means nothing now but at the time it meant a lot. Something happened at school and you would get rewarded with a sweet. Everyone else would get a sweet or a mars bar or something and I would get an apple or an orange something like that. It was just (shrug).'* Oliver (D)

*'There was one occasion when my friend asked me to go on holiday with her and her parents wouldn't let me because they were scared in case I took a fit and er it sort of stuck in my head for ever really which really hurt me and it was a bit odd because her Mum is actually a nurse...So that sort of hurt me a bit because if you're like a nurse, you should really know I don't have fits.'* Anna (D)

Those who expressed most impact from health status at school (seven in the sample: four males, three females) had cystic fibrosis or arthritis. Some of these individuals had missed months of school attendance, attained few or no standard grades and also, on occasions, suffered bullying or teasing because of visible impairments.

*'The hardest part was getting up in the mornings and still is. There were some days when my Mum would have to physically lift me out of bed, dress me and take me to school and in the 4th year at school when I was doing standard grades, it started spreading, it went into my hands and my hands were always swollen and I think what really summed it up one morning was my Mum came through to my room, I can remember it quite clearly, I was doing chemistry homework, trying to write up the stuff but I just could not write... I always had problems with bullying at school for a very long time whether it was directly because of my illness or not, if I was easy target, I'm not sure.'* Andrew (JIA)

*'I think it was because I was always in hospital em I missed so much of the work, em when I was going into hospital and when I come out I'd be pages and pages behind the rest of the class and it got to the stage where the teacher would just have to say well you just go on to this page what the rest of the class is doing and I keep missing pages, about half a book's worth and all that, and it got to the stage where I was so far behind and I was missing so much work, and it was annoying that way'* Eddie (CF)

The school lives of four individuals in particular were punctuated by illness, treatment and hospitalisation (a few estimated having been absent for two weeks every other month all throughout their school lives). As a consequence, they were always chronically behind and three ended up leaving school at 15 with few or no qualifications. Only one respondent who was off sick for long periods recalled receiving extra educational tuition (see Iain's comment previously). Some had to re-sit

school years and/or reduce the number of subjects they studied in order to keep abreast of school work.

*'Primary school was OK, I was never really ill at primary school but gradually by the end of second year and into 3<sup>rd</sup> year high school that's when it started to get worse. Because I did 2 third years. My first 3<sup>rd</sup> year I was off for 3 months but not straight, it was like back for two weeks and then off for a week, it was just on and off and I could not keep up and it was just at exam time and I was actually in hospital when everybody was doing exams. So I did not do them my Mum went to the headmaster and said could she repeat a year so I did it again.'*  
Vicky (CF)

Even when well enough to attend school, lessons were often interrupted by the need for treatment. These regular disruptions meant that a few respondents found it difficult to progress well with schoolwork. They were also furthered disadvantaged by schools' somewhat laissez-faire policy of fitting pupils into the syllabus of others in class. Eddie, a respondent with CF, recalled having to jump work to keep level with his peers, ('just go on to this page') without being given time to catch up or develop an understanding of work covered previously, (*I kept missing pages, about half a book's worth*). All his school subjects were similarly affected.

*'...even in my English class I would be going out for my physio, I'd have to go and get my treatment done, and I would come back and maybe they would all be reading a book and they would say, Eddie read through that chapter and I would be reading along and I would not have a clue, I would be just reading out the words and not a clue as to what the story is all about. At the end of it they would say, so what did you think of the book and all that. I would have to be honest and say not a clue'* Eddie (CF)

Two other respondents reacted to their situation by becoming disinterested in studying and generally giving up on school. Whilst one was frequently in hospital requiring treatment, another was absent seemingly as much through truancy as with CF.

*'I missed quite a bit at times when I was not well, but I caught up when I went back to school. To be honest it was crap anyway.'* Gary (CF)

*'At primary, my Mum said could you not have stayed at primary all your life because I used to do all my projects, I used to use my brain. But at high school, I used it for other things. I used it to antagonise folk and annoy folk all day. But I reckon I would have been good because I liked Maths and English and I could do the work but secondary school well...I was one of the rebels, I went down that road. I was always off (from school), half the time I never*

*bothered going...sometimes I was ill but 90% of the time it was through my own choice.'*  
Fred (CF)

Xanthe was the only respondent in the sample who attended a special needs school. Her experiences of education were similarly negative. She was a bright child but felt restricted by the educational regimen adopted by her school which did not offer the wide range of subjects provided in the mainstream system.

*'Special needs from start to finish, I went there because there were no or very few primary school physically adapted for kids in wheelchairs, it was not the done thing. The difference being in mainstream you could maybe do standard grades, you had a choice of French, Spanish, German, Italian. We just had one French or Art. You did a general science standard grade not biology, chemistry, physics. We did CSS which is contemporary social studies which was like geography, history, modern studies current affairs environmental studies all those things rolled into one. And that is what I did. I did office studies and French and a lot of them didn't do that'* Xanthe (JIA)

A striking feature to emerge from the reminiscences of these respondents was the apparent lack of effort by schools to provide extra educational support for those with long-term illness. Whilst this is a small sample, the uniformity of reports on this issue would seem to suggest that very few attempts had been made by teachers to counteract deficits in education caused by absence. The lack of educational attainment by those most affected by their condition would also appear to support this view. It is possible that there is a lack of guidance within the school sector towards these groups of people perhaps fostered by a fatalistic attitude about the prospect of favourable long-term outcomes (both health and educational).

Accounts by individuals when talking of former times, however, are reliant in part on a reasonable degree of accurate recollection. Memories can be coloured by subjective negative feelings, critical events and imagined or real hurts. The next sections cover both past and contemporary attitudes of respondents in relation to their health and the ways in which lives were regarded and experienced.

#### **5.4 'Getting by and being different': the impact of illness in childhood**

All respondents appeared well informed about their condition and the possible complications of their illness. About a third spontaneously talked about the need to keep fit or to take regular exercise in order to better manage their condition. These types of comment were mainly but not exclusively made by men in the sample and were not confined to any particular disease group.

*'I do try to look after myself, stay active and do some sport...I do know how to look after myself physically...I think building up my muscles has protected my joints to a certain extent as long as you're not overdoing the running stuff and wearing them down at the same time; it's like little bits in moderation'* Andrew (JIA)

*'I go to gym and I play tennis and swim and stuff like that...If I didn't have to do it, I would be a couch potato but it does me good'* Yvonne (CF)

Male respondents considered it especially important to have kept active as a child during the formative years of development.

*'When I was at school I had to go for a run during probably a critical time in terms of lung developing and things like that and if I had not done that my health could have been significantly less healthy than it is now.'* Quinn (CF)

*Still I was very active as a child. Not quite so active now but I think if you are active in your youth I think that stands you in very good stead for the age I am at now. You need to keep doing activities to prolong that. When I was at school I used to play rugby and do all these things.* Colin (D)

Males were also most likely to discuss the effects of chronic illness as a child in terms of their ability or lack of ability to undertake or maintain sport at school.

*'Well I woke up, it was the morning I woke up and had fluid on my knee I had a game that day and I went and like there was, they were going to decide if I could play, they said look we don't know what it is so you're not playing and it just like everyone assumed that they all thought I'd just go the doctors and they'll just put a wee bit, they'll take the fluid out and I'll be playing the next week but it never quite panned out like that '* Will (JIA)

*'When I was younger I couldnae really play football, there were certain games I couldnae play, I was always good at badminton because it was just your own wee box you were in and I said to myself well there's just this box that I have to run in and I could usually keep up*

*with it, but when I was playing football I was nearly killed running about, chasing after the ball and it was just too much for me, you know' Fred (CF)*

By way of contrast, females tended to recall either less of an impact of a diagnosis at school age or spoke of a disruption to social events and/or to school work.

*'I can't remember it stopping me doing anything' Bryony (JIA)*

*'It was never oh everybody staring at me because there is something wrong with me, it was never that. I thought about it like being special, special different, a little diva' Lara (CF)*

*'I wanted stuff to do (in hospital) but they were like oh Beth get yourself better then come back but when I came out of hospital we were doing standard grade maths and I just couldn't catch up with the volume of work' Beth (D)*

All respondents were reportedly proactive in the management of their condition. There was a gender difference within the sample in terms of how chronic illness was perceived to impact on school life. Males most frequently discussed health status in relation to sports-related activities perhaps reflecting the importance of prowess in this area amongst school-age boys. Females, however, tended to refer to the ways in which symptoms of illness occasionally prevented them from taking a full part in social events or how they interfered with school work. Whilst some negative experiences were encountered, for the majority, growing up with a chronic condition seemed largely a process of getting by. The depiction of chronic illness in childhood as inevitably one of behavioural, emotional, educational and social disturbance did not hold true for most of the individuals in this sample.

### **5.5 'Making it part of day to day life': a self-styled approach to illness**

Respondents across all disease groups predominantly displayed a self-directed, individualistic approach to their condition. They said they rarely made use of formal organisations for support, such as Arthritis Care, the CF Trust or Diabetes UK, except occasionally for financial assistance, nor did they seem to seek direct care from partners, friends or families. Instead, they relied fundamentally on their own sense of

judgement to manage their condition. They tailored treatments to their situation, altered times of medication, adjusted dosages and omitted therapies to suit their day to day lives.

*'If I'm travelling or going away, I sometimes forget my symbicort (inhaler) but it's not critical obviously it's beneficial in the long term...in terms of day to day routine, I don't do things like physio or whatever. I'm a great believer that you live life and if you can make it part of your day to day routine, going to the gym or going for a cycle or whatever then that's great but if you end up spending your life doing your physio instead of living life you've kind of wasted it' Quinn (CF)*

This attitude was not a rejection of specialist advice, although criticisms were levelled on occasions at particular health professionals; rather it arose out of a desire to accept and take responsibility for their own health state. Treatments and medication were regulated accordingly.

*'I do tend to vary it (laugh) I take the same amount of my long-acting in the morning and at night generally although sometimes I have a bit extra at night, if I'm a bit high or a bit less if not. Generally these are the two that stay the same, all the others I vary (laugh)...I told my specialist I was doing it and you know she was quite happy because my control was OK' Beth (D)*

*'I stopped (taking tablets) completely for about a month then I was having a bit of pain so I started them again and now I usually take one 2 or 3 times a day and it keeps me normal basically...I'd rather not take anti inflammatory for the rest of my life so I just wound them down, a programme of cutting them out, it wasn't so much on the advice of the doctor but I discussed it with the doctor the last time I went to see him' Xavier (JIA)*

For the majority, having a long-term health problem was generally a personal rather than private affair. Partners and families were perceived as helpful but only essential by those most affected by their diagnosis. In fact, a few (all females) said they deliberately avoided discussing their state of health with close relatives to avoid distressing them unnecessarily. Day-to-day concerns about illness and treatment were part of the fabric of lives and respondents took the view that they were owners of their body and they knew what worked best for them. However, as the third quote shows,



discussing the vicissitudes of living with a long-term condition, could become tedious for some family members.

*'I talk quite a lot with my sister (who has CF) not my husband. Obviously my husband is around much more but he gets a bit upset about it.'* Yvonne (CF)

*'I've a very strong relationship and actually I have always had very strong relationships with people and um good friends but I don't believe you should impose on them, even on your husband with unnecessary crap, you know there's a lot of unnecessary crap and I still very much think I need to do this, I need to figure out how to think about it and what I feel about it before I can go and talk to Peter (partner's name) or talk to anybody else.'* Sarah (JIA)

*'He (boyfriend) phones me every night to see how I am em he doesn't, I think he understands in a way em but I don't know if he, he phones me every night to see how I'm getting on, how my day's been, how I've been feeling and things so he does listen but you can't tell him too much because sometimes he gets bored too of listening which is fair enough because everybody gets bored listening sometimes'* Kate (JIA)

Along with the personal nature of living with a chronic illness, a few respondents who had a job said they were discreet, even reticent on occasions, about taking medications at work. This attitude appeared to be a particular feature of those with diabetes whereby individuals are required to inject insulin regularly throughout the day and particularly at mealtimes. For the main part, the explanations given were out of consideration to others who might feel squeamish about the sight of needles or the thought of injections. One man, however, required privacy for injecting and he had changed his treatment regimen rather than be placed in a situation where his health might be at risk.

*'I'm quite open in front of my friends, with other people I've met for the first time, I wouldn't do it in front of them, I'll go out of the way and if they say, I'm uneasy about needles or something, I'll go to a different room or something but I won't hide it, I'm not scared'* Peter (D)

*'I've started doing it (injecting) in my stomach now so if I'm out, I just do it at the table under the table. You don't really know if people like needles generally so if I'm in an open space and there are people watching then I'll go to the toilet, because I know my step mum's doesn't like needles at all and it makes her feel quite queasy'* Nicola (D)



*Oliver (D): I like a bit of privacy, one of the worse things is when you're out on site and you could be in a building site in the middle of nowhere, I mean that's a nightmare, I wouldnae do it in front of people, I don't know why, I've always been like that... That was another point that I made to the doctor to change back to 2 a day because it was not practical for me.*

*Helen: So at the time were you forced to do it in front of people?*

*Oliver (D): No, I would just not do it.*

Respondents of both sexes discussed changes in attitudes towards medication and treatment over time. Transition periods such as reaching adulthood and getting a job or entering higher education were obvious trigger factors but a shift in disease status was also instrumental in altering previous habits.

*'I went through this really bad bit of not being (not checking blood sugar levels), and then slowly just because of my every day being sort of different, changing all the time and I was like what day is it, what morning, it was more often and then I got myself sorted out' Anna (D)*

*'At the moment with my arthritis I am quite sore as I am actually coming off methotrexate because I don't want to be on it as I don't like it. When I am on it, it makes me feel ill, sick and I was not one for being sick before that. I've had viral infections and stuff like that while I've have been on it. You know you get the little booklet with the side effects on it, after reading it I don't like the side effects you could possibility get, the dangers with it so I'm coming off it because I don't like it' Jackie (JIA)*

*'It's quite annoying having to test my blood and do my injections, I do it all the time about 7 times a day because my blood sugar level went really high and that and I just worry about it, I just constantly test and I hate having hypos as well so if I feel funny I test it straightaway' Cara (D)*

Self-care strategies, then, were often complex and dynamic and were altered to suit particular circumstances and contexts. Decision-making about treatment was rooted in the personal and social conditions of respondents' lives. These young adults had lived with illness for many years and had learnt to know and respect their bodily responses to situations and treatments. Changes to routines were often made through a process of controlled experimentation as some of these quotes make clear (see Xavier's and

Beth's quotes on p. 141 and Anna's and Jackie's quotes on p. 143). Managing one's condition in this way, however, did not constitute a rejection or lack of compliance with professional advice. Rather it reflected the stance adopted by these respondents who viewed themselves as unique individuals who were obliged to make modifications to treatment regimens in order to fit them into personal needs and goals.

A somewhat surprising finding was the lack of active input in the health care of most respondents from close family members or partners. Whilst carers might have provided an alternative perspective to the one obtained by this sample, it nevertheless reflected the individualised approach to illness practised by these young adults. Many respondents, however, frequently made reference to the importance of parents and family life whilst growing up with illness. The ability to cope with symptoms and impairment as an adult was seen to be due in part to the influence of significant others, usually one or both parents, on formative years. Those who came from turbulent backgrounds were notably less forthcoming about the beneficial aspects of parenting on their capacity to manage lives. Extreme parental responses such as over-protectiveness (usually termed mollycoddling by respondents) or abandonment of responsibility as in denial of illness were equally ridiculed as inappropriate behaviour by all those in the sample.

## **5.6 'It's just an everyday thing': the quotidian nature of illness**

For most individuals in this sample, living with a long-term condition seemed second nature. The treatment regimen or effects of illness were invariably taken for granted and, although these occasionally intruded, they generally did not impose directly on day-to-day lives. This feature characterised many of the respondents' narratives and was particularly apparent in the accounts of those with diabetes.

*'The drugs and things they're just routine so it makes you, I can't even imagine what it would be like not to have it now' Diane (D)*

*'It doesn't annoy me, it's just something I've become accustomed to, it's actually become a habit, I have forgotten before, I've been sitting down eating my dinner and I might have been too busy cooking or something and I forgot (laugh) and then I would have to go and get it but it's just a habit' Beth (D)*

For many, it was the perceived longevity of their condition that ameliorated the bothersomeness of treatment. Having to regularly check blood sugars or take medication were normalised into the routines of lives to such an extent that they had become everyday activities.

*'I've had diabetes for such a long time anyway that it's just an everyday part of life...It's just there, I don't know any different really' Nicola (D)*

*'I see it just as I don't know as life basically, I don't see it as a burden, as a bag that I put on my back or anything, I don't see it as that' Peter (D)*

Only a few severely affected individuals (three or four in the sample) experienced the effects of illness as burdensome and this perception could fluctuate according to context and disease state. One woman with severe arthritis, for example, talked extensively about the variability of her condition and assessed her capacity to fulfil daily tasks according to times of the day and mood as well as to the state of her health.

*'Mornings are very rarely good for me...Some days I can get up and dress myself and other days I cannot lift my head off the pillow. My dinner last night ended up on the living room carpet because I went to cut it and it went flying off the plate and it's stupid things like that Today is a relatively good day, it's nice outside, the sun is shining I feel good, well, I feel better some days and I open the blinds but if it's grey and it's drab and I think, back under the covers, do not come out' Xanthe (JIA)*

For those with severe impairment, however, it was the knowledge of slow deterioration in health status that wreaked the most havoc.

*Eddie (CF): Like even a couple of years younger I was running about playing football and now I couldnae do that as I get out of breath, even at my best I couldnae do that*

*Helen: So how does that make you feel?*

*Eddie (CF): Ay, not really too bad as you get used to it you know, it's that slow, you don't really, you don't notice it, you know, it happens that slow*

*'A couple of years ago I would say I am feeling good today and I want to go out and I would be sitting with a face like a wet weekend because there was nobody that was free, where could I go, who could I phone. Now I have a list of people that I should be phoning and I do not have the energy. I keep going over the same things again it's shocking' Xanthe (JIA)*

Disease severity played a part in determining how intrusive effects of illness could be in the lives of these young adults. Most, however, were able to discount bothersome symptoms and regulate treatments accordingly. The variability and unpredictability of illness in all cases could occasionally undermine carefully planned activities. These young adults had learnt to live with the fluctuations of illness and, for the most part, these were an accepted consequence of their condition. Chronic illness was experienced dynamically which involved frequent assessments and responses to changes in symptoms and circumstances over time. Mood and sense of self clearly affected how conditions were experienced and most emphasised the importance of not letting illness rule their lives and to focus on what could be achieved rather than what could not be.

### **5.7 'I don't rely on my body, it's all in my brain': the embodied sense of self and effect on self-esteem**

At interview, respondents were invariably confident about their own abilities. The majority described themselves as determined individuals who did not feel particularly limited by their health status. They appeared relaxed about their condition and discussed situations when they had forgotten to take medication and how they had adapted their lives to fit round health concerns or treatment regimens. Two respondents, by way of contrast, seemed less assured in themselves and one of these was almost excessively vigilant over her state of health. Cara, who had diabetes,

reported being anxious about her treatment and checking her blood sugar levels several times a day.

*'I just worry about it (blood sugar levels), I just constantly test and I hate having hypos as well' Cara (D)*

Although Cara tended to question her own abilities, she did not blame any lack of self-belief on her health status. For Cara, low self esteem was not a consequence of her diabetes nor was her condition seen as contributing to her feelings of uncertainty. Its effect, however, was manifest in the way she perceived and responded to her diagnosis.

*Helen: And when you set out to do something, do you feel that you can be successful at it, achieve what you want to achieve?*

*Cara (D): No, not always'*

*Helen: 'Why's that? Do you think that has anything to do with your diabetes?'*

*Cara (D): 'No, I don't think so, I think that's just me'*

Most others with various types of disease reacted quite differently. Their determination to be successful generally counteracted any negative effects of illness.

*'I'm a very strong-willed person. If there's something I want, I will go for it and go and try and get it.' Anna (D)*

*'You just have to make your mind up and you can do it.' Beth (D)*

*'I do not want to be treated like see that wee girl with arthritis over there. I generally tried to achieve a lot more than other people.' Jackie (JIA)*

*There are not many things that I have set myself out to do but the things that I have done well I suppose yeah I get on with it. I did the Great North Run for CF this year. So well yes I set out to do it and I have done it and I will do it again next year' Lara (CF)*

A few with more severe forms of impairment made a distinction between mind and body. They spoke occasionally of their resolution to get on with things only to be let down by the effects of illness. This lack of control, however, was not a constant feeling but did lead in some cases to a perception that their bodies were somehow untrustworthy and unreliable.

*'I did go through a period of time when I thought, I was quite low and I did think oh fuck what's going to happen next you know, bits of my body keep letting me down, I have no idea what's going to go next.... When my joints started acting up again then I think oh fuck here we go again you know but I do remember thinking very negatively at those times'. Sarah (JIA)*

*'I feel like it does not even enter my mind because it's all in my brain, I don't rely on my body as I have not relied on my body since I was 5. Everything has been trained up in my brain so everything that I know and everything that I do is going to be connected to my mind rather than anything else.' Iain (JIA)*

*'When you are feeling ill you become more philosophical, feeling shit because you are sitting on your back and thinking about things day dreaming and wee scenarios running through your mind so you can start writing and become creative.' Gary (CF)*

During times of flare-ups or exacerbations of illness, many respondents described how easy it was to sink into negative feelings. The importance of positive thought as a coping strategy was apparent throughout many of the narratives (see quotes from Beth, Anna and Jackie in this section p. 147 and those of Quinn and Colin in subsequent sections p. 150 and p. 151 respectively). In order to make sense of bodily dysfunction, some individuals ascribed to a kind of Cartesian understanding of themselves that paid no attention to the interrelationships between mind, body and environment. This response reflected the tension among some young adults between lives as desired and lives as experienced and the trade-offs implicit within these processes.

A common feature of those with chronic illness is the prevalence of co-morbidity arising as a complication of the first diagnosis or as a result of two or more conditions occurring side by side. In spite of the young age of these respondents, about a third reported experiencing or having experienced other health problems. The next section describes how these were interpreted and dealt with by individuals in the sample.

## 5.8 The experience of co-morbidity

Ten respondents in the sample reported some other health concern alongside their long-term condition. For four individuals, these were the result of complications of their original diagnosis such as liver disease and lung pathologies associated with cystic fibrosis or cataracts due to diabetes. There was no obvious connection in other cases. Such co-morbid illnesses made respondents feel vulnerable; some wondered if these could be attributed to their existing disease state or whether something else might be occurring.

*'I was really ill last year, I don't think it was anything to do with my diabetes but it was early on last year I started to feel really ill. The doctors thought I had Crohn's Disease which being diabetic you are more prone to getting stuff like that. I had all the symptoms of Crohn's Disease, lots of pain, I was in agony for months but it eventually just cleared up and I've had more tests and they do not think that it was, they think it might have been something like Crohn's Disease that has just gone for some reason.'* Cara (D)

*'I get abscesses quite often and they don't know why I get them and basically they usually happen when I bruise myself it turns into an abscess so I've been getting them, I basically had about 30 since I was 18 months old. I've had them in my mouth, I had them on my face I have never had them on my chest that is one place that I have not had them. And on my legs and on my arms and there (demonstrating) is that and I have had every blood test under the sun. I was sent to a specialist in Newcastle to find out exactly why I am getting these but they can't find out why I get them and what the condition is they don't know if there's a link to the arthritis or not but they think there might be so that is always there in the background for me that I am susceptible to them. My general health never really feels 100%.'* Iain (JIA)

Whilst individuals might be uncertain over the aetiology of co-morbidities, their management to illness (whatever its form) stayed remarkably unchanged. Few deferred to health professionals for guidance or relied on anyone but themselves to take charge of their health. After initial set-backs, individuals became pro-active and their accounts were interspersed with comments about their need to remain positive.

*'I reckon I am still recovering (from a stroke). Other people say I recovered after a year. I am not at the level of physical fitness I would like to be and even over the last few years there has been a lot of change. But you see very little change for years and years and all of a sudden you notice something and then you have to keep working on it. When I first had the stroke the doctor was, the consultant actually was a complete muppet, he was so pessimistic. He said to my parents that anything I got back would be a bonus. I was thinking you*



*bastard how can you say that just after it had happened you should be more upbeat and stuff.'* Mike (CF)

*'There are moments where having just had thoracic surgery and a couple of other things, there was a spell for about 4 months that, it was a pain in the backside but when you come out the other side of that yes it might have been a bit of discomfort going to the gym but you just go to the gym and get on with it and it makes you better. So I do not actually see that as limiting my life style I just see that as a hurdle in my track to just get over.'* Quinn (CF)

*'Each consultant is only interested in their own specialty so a lot of things probably get missed um my GP did say to me that it's possible I could be labelled as lupus because I also had a heart problem briefly but I don't think I have so I've always resisted being labelled because it seems to me unless you're in charge of the labelling, which some chronically ill people are now, more and more I suppose then you've no control over it, I don't like labels, I don't like putting them on people, I don't like people putting them on me. So in terms of support, the way I deal with it is to get on with it.'* Sarah (JIA)

Co-morbid conditions occurred in both sexes of respondents in all disease categories. They did not appear to be dependent upon severity of disorder so that those who might be classed as having 'milder' forms of illness were not immune from developing subsequent health problems. Respondent accounts made about health services in general and health care professionals in particular with regard to co-morbidities deserve some mention. One feature to emerge was the uncertainty over the nature of new signs and symptoms which caused a great deal of anxiety on the part of individuals that was often not addressed by doctors or hospital staff. A number of respondents highlighted the length of time it took to obtain any form of diagnosis, provisional or final, between presentation of novel health problems and receipt of treatment. The lack of support and personal engagement of health professionals in the care of respondents was also seen as a failing. Whilst these individuals were actively involved in self care and seemed able to deal with the complications arising from illness, their self-reliant approach to managing symptoms was adopted in spite of professional intervention rather than because of it. In the face of unfamiliar circumstances, the ability to make appropriate decisions about health care may also be

undermined. To avoid the experience that Mike encountered (p. 149-150), discussions undertaken by health care staff about effective treatments and recovery times require to be handled sensitively. There is evidence too that medical and nursing professionals do not always diagnose and prescribe appropriately (Rudd, 1992) and prognostic assumptions in the early stages of illness can be misleading.

### **5.9 'I don't like labels, I don't like putting them on people and I don't like people putting them on me': self-definitions of illness**

Most respondents in the sample disliked being labelled as chronically ill. This classification was perceived as unhelpful in many ways. Although a diagnosis offered avenues for treatment, it could also serve to define and limit the potential of one's self as an individual. Both males and females in the sample felt that undue emphasis or attention on their condition could become destructive.

*'I think if you label somebody early then they take the label with them and act to the label rather as themselves...I have moved on. I see myself as yes I have CF but it is not the bee all and end all. Ursula (CF)*

*'As soon as you start treating people, I mean you are not different just because you have diabetes you just have to manage your medical condition. You could see that it is in a way like being an epileptic but it's not as there is nothing you can do to manage that. So in as far as special treatment I think it's great for people to be aware of the condition you have but to treat you anything but normally would create a stigma. It allows you to fight on' Colin (D)*

For many in the sample, a focus on their disease state as if it were an essential characteristic was demeaning and diminishing. It robbed them not only of a sense of individuality but also, potentially, of the capacity to participate fully in society. Some respondents spoke about this aspect obliquely, making analogies to cups being either half full or half empty depending on one's perspective. The quotation overleaf underscores the types of statement frequently made by respondents.

*'You have to be positive, instead of using CF as an excuse that you cannot do it. CF is the excuse that you should be doing it' Quinn (CF)*

A few respondents even denied having a chronic illness. Occasionally this was an expression of doubt over the strength of the diagnostic evidence underlying their disease status, but for the most part such denials were associated with individual notions of self-definition. Admitting to a long-term condition had the potential of altering one's perception of one's self, it could make you assess yourself as different which was not what was felt nor what was desired. Respondents repeatedly stated that they did not feel anything other than 'normal' yet they were sometimes deprived of this normality by others.

*'I hate anybody saying no, no, are you alright if they bump into you, and you know, like all this pity for your disability and you know if somebody was in the other end of the living room and was smoking they say like oh no, I'm sorry and I should have opened the window and they make a big fuss over it, you know what I mean, so I would rather be treated like everybody else, you know what I mean, not for people to go out of their way and think me different.' Eddie (CF)*

Sometimes a process of labelling seemed to be most readily practised by health care professionals themselves.

*Peter (D): 'Some people do treat me differently, it's hard to explain, some people do and some don't, it's just the kind of person they are at the end of the day and how they feel and how they react, if you can communicate with people on a one to one it's easy for me to chat away to let you know how I feel'*

*Helen: Those who you feel treat you differently, how do they make that apparent?*

*Peter (D): Em to be honest I've never met many people like that, well to be honest it would be doctors (laugh), that's the only people I couldn't honestly say '*

*'I know they (hospital staff) don't mean to, but they stop making you feel normal, normal in the sense of normal, I mean you are abnormal, you are a CF patient, and that is how it goes. You are abnormal you have abnormal airways, you have obstructed airways so you are abnormal, you are not normal to them so they make you feel different, they do not mean it but they just do it, it's just the way they come across. It is not their fault, it is not a bad way, no bad intended. They care about you and they want to help you that is why they're there' Gary (CF)*

As well as an aversion to being labelled as chronically ill, the vast majority of the sample (number = 26) did not perceive themselves as disabled. Disability as a term carried very negative connotations for many respondents, the word being associated with extreme restrictions of activity. Such restrictions were not felt to be relevant to most of these individuals and the limitations that they themselves experienced.

*'I don't class myself disabled at all because I feel like 9 out of 10 days, ask me anything and I would be able to do it. If you're disabled there's a going to be a good few things you can't do, that is the way I see it and there's nothing I can't do on a good day, I suppose I can't run a marathon, extreme physical exercise I can't do but that's alright because a lot of people can't do extreme physical exertion and that doesn't make them disabled'* Iain (JIA)

*'I don't have a disability you know, I might have joint problems and you know I did go through a period of time when I was particularly low and I thought oh fuck what's going to happen to me next, you know...and I did think if I have to label myself do I have a chronic illness but it's not a continuous thing and I don't know how to answer that, from day to day it changes and when I'm having problems with my knee as now, I think it's too easy to let it invade every bit of space.'* Sarah (JIA)

Thomas (1999) makes a distinction between 'impairment effects' those restrictions of activity directly connected with being physically, sensory or intellectually impaired and 'disabilities', those restrictions that are socially caused. Many of the respondents in the sample seemed to instinctively endorse Thomas's definition by their conceptualisations of health status.

*'I wouldn't say I was disabled, I would say I have an inability to do something...It is only me that would make it a disability, but because I'm not one to sit and take any rubbish that people give me or anything like that, I generally try and achieve'* Jackie (JIA)

Most respondents denied any sense of difference that would mark them out as disabled compared with able-bodied peers.

*'I have always been the type of guy that if I want to do something I will work round my problems rather than not do something I will try to work round them to get on with what I want to do.'* Theo (JIA)

*'I really do not think about my CF. I have said this a few times now it is only this year is the first time I've really thought my CF a lot more mainly because I was raising money for CF and I was talking about it to people when I was asking for sponsors'* Lara (CF)

In fact, only four respondents in the sample identified themselves as being disabled or at least discussed the notion of disability in relation to themselves. Two of these had a diagnosis of arthritis and one used a wheelchair because of severe impairment.

References to disability pepper their accounts particularly in relation to education and experiences of work. For these individuals, classifying themselves as disabled carried no pejorative overtones although those who sought to exclude or pity them came in for censure. One woman with cystic fibrosis who had recently reduced her hours at work reacted ambivalently towards any concept of labelling and only assumed such an identity with reluctance.

*Helen: Do you think of yourself as someone with a chronic illness or as someone with a disability, I mean do you think of yourself in those terms or not?*

*Yvonne (CF): I try not to but you know when, I suppose you do to a certain extent to try and justify why you are reducing your hours of work and stuff.*

Being labelled as chronically ill was largely felt to be restrictive. Labelling in any form was seen as something imputed by others primarily to set limits on what could be achieved. This viewpoint reflects the theoretical stance taken by symbolic interactionist researchers such as Goffman (Goffman, 1963) and Becker (Becker, 1963) whose seminal concepts have become part of the discursive lexicon of Western society. They developed the idea of illness being viewed as a mark of disgrace that carries with it a series of undesirable attributes which may be negatively construed both by the person themselves and by others with whom they interact.

For these respondents, chronic illness as a defining status was neither desirable nor meaningful. Individuals invariably had access to other identities particularly those who were employed which were infinitely preferable to that of illness. Associated with

this dislike of being defined by health status alone, was the notion that respondents did not view themselves as essentially different. On the one hand, living with symptoms of illness was part of their normal, everyday experience and on the other, they frequently did not perceive themselves as being ill (see previous comment made by Iain on p. 153 and quote by Lara p. 154). Having a long-term condition was regarded in the main as a controllable state and something that did not (or should not) mark them out as different or set them apart from others in society.

Perhaps as part of this desire for 'normality' was the reluctance by the majority to associate themselves with a disability identity. Some respondents, in fact, expressed pejorative comments about disabled people possibly as a distancing strategy. The discourse and celebration of difference as broadcast by the disability movement seemed to have little or no relevance for these young adults with chronic illness.

### **5.10 Attitudes towards others with long-term chronic illness**

Several respondents talked about others with the same disease or chronic condition. Sometimes this was because of a similarly affected sibling, at other times it arose spontaneously through discussions at interview. Usually the context was of other individuals displaying markedly different attitudes or characteristics to themselves. Such people were regarded as being more representative in their behaviour and attitudes for that disease state, conforming to a more classic type. This perception was particularly apparent in the accounts of females in the sample and those with cystic fibrosis and arthritis.

*'I always feel guilty when I go to the chest clinic I hate going to the chest clinic because I feel guilty for being there because I think I am a fraud. All these questions I find do not affect me so I feel guilty' Lara (CF)*

*I can't stand these people who go on and on saying I can't do this and I can't do that. I think that's quite common too. I remember I went with my pal Pete to get his wrists injected. I could not believe it as he was so pathetic, I said, why do you let it get to you. It's a health*

*routine thing you are getting done, you are just getting injections, it really does irritate me.'*  
Jackie (JIA)

*'I see myself as yes, I have CF but it is not the bee all and end all, whereas my brother, knowing how he has grown up and how he has played to his CF he has had to, to get to whatever....He is a completely different mentality to me and I think if he didn't have CF, he would have something else to worry him'* Ursula (CF)

In a few cases, comparing oneself with others could be reassuring particularly if it meant that illness was not experienced solely by one's self.

*'You go downhill, it's that slow, you don't really, you don't notice it, you know, it happens that slow but people, everyone's CF is different, you get people who deteriorate quicker than others so and that's quite scary when you see that happen to other people even yourself when you look back to a few years ago...You can get a bit depressed in thinking that you're the only one that lungs is deteriorating and nobody else's is which is not very nice to say it, but it makes you feel better that other people's got it but at least I know that I'm not the only one, you know'* Eddie (CF)

Some respondents (particularly those with cystic fibrosis and arthritis) felt that they were not typical of their disease type. It is difficult to know precisely how to interpret this finding. It may signify a desire for individuality or be linked to the denial of an illness identity. Goffman (1963) referred to the stigma of illness and the sense of the stigmatised individual as "being 'a normal person', a human being like anyone else, a person" (p. 17) whose feeling of difference arises because of the attitudes of 'normals' to them in social relations. Perhaps this response then was simply a wish not to be typecast in a patient role. Indeed, the management of health care structured as it is under broad disease pathologies encourages division of chronic illness into discrete conditions. It is easy for individuals in such a system to be conceived of as 'diabetic', 'arthritis' or as a 'CF patient' and this form of labelling behaviour may engender stereotypical definitions. As an alternative to feeling objectified by illness, these young adults might merely have been asserting their need for self-characterisation.



### **5.11 'I don't think they should be preaching to you about what you should or shouldn't do': attitudes towards health care staff and the management of chronic health care services**

About a third of respondents felt that their experience of hospital and outpatient care had been consistently good. This response cut across gender and disease group. The frequency of clinic visits was generally deemed to be appropriate and several found it reassuring to be seen regularly particularly if it was by the same health care professional. Despite not being associated with any of the hospital departments at the time of interview, there is a possibility that my nursing background may have affected the amount of criticisms received about hospital staff in narrative accounts. This factor is an unavoidable element of the researcher-researched process.

*'I think it is about right just now because they are trying to look at my tests and things like that but before it was six monthly. They just do it in line with how they think you're doing.'* Nicola (D)

*'They already know everything about us so you don't actually have to explain to them, they can sit and tell you things about it, you know, it's good, you can sit and talk to them.'* Eddie (CF)

*'It is just something that I have always done ever since I since I was diagnosed with it and I would attend clinic 3 or 4 times a year and now I go to the Scottish young adults clinic which is 3 times a year. It just ensures that you are doing everything you should be, eye checks and that sort of thing. I think it's just reassuring particularly with eyes I would want to know that I'm not doing myself any long-term damage'* Hugh (D)

Certain members of health care staff came in for special commendation. These were usually but not wholly from the nursing profession. These same individuals were praised repeatedly by different respondents within the cystic fibrosis and diabetic groups. These services both had access to nurses specialised in the areas who operated autonomously and within multidisciplinary teams. Arthritis, on the other hand, was managed mainly by doctors in the outpatient service and notably, in this group, no one staff member stood out. Susan, a diabetic specialist nurse, was appreciated for her

down-to-earth approach to care and also for the specific empathy she could provide, she herself having diabetes.

*'Susan is really good, she was really good when I was ill, ringing us all the time and she was really helping us out. Being diabetic as well, she knows, she understands.'* Beth (D)

*'We sit and have a good chat, Susan and me so it's really good. She helped me out an awful lot at the beginning cause my diabetes was a bit haywire and my control wasn't very good. So slowly Susan has just been working away with everything with me and my control's got better.'* Anna (D)

Morag, a nurse who worked in the CF unit, moved post during the period of interviewing. She alone seemed to have the confidence of respondents with cystic fibrosis and some of them especially mourned her loss.

*'I have asked for results before whether it be culture and sensitivity or blood results, I've asked what do they look like and been told, oh they are fine. They do not actually tell you the figure although I have asked about 5 or 6 times. This is an issue in relation to the change of nurse staff and Morag was absolutely bloody fantastic, She was wonderful and she got to know the people as individuals whereas I've had probably more dealings with the CF unit in the last year than I've had for the rest of my entire life almost and they know less about me as an individual and what I want in my life and what I am doing than Morag did the whole of the rest of the 12 years that she was looking after me.'* Quinn (CF)

The outpatient set up, whether it was multidisciplinary or run on more traditional grounds, occasionally came in for comment. Whilst some resented the length of time they had to wait to be seen, others liked the partnership approach embraced by some of the health care teams.

*'He (the doctor) just makes sure everything is all right and that me and Susan (nurse) are working out the problems, that me and Susan are working at it. It's a really good way of working it'* Anna (D)

*'I will need because the hospital has changed it clinics to during the day now, I need that time off in the afternoon, but apart from that it's OK, it just the usual, sitting for 3 hours waiting'* Andrew (JIA)

Several criticisms, however, were levelled at health services throughout the interviews. These ranged from personality clashes with particular health care staff through to

complaints over the type of care management being provided. Respondents specifically disliked the didactic approach practised by some health professionals.

*'Every now and again they will say, well you know you are seriously ill, well I know that, I do not need reminding, I have made a hell of a difference to my health, I've put on 10kgs, I have put the weight on healthily, I have got myself to grip with things. If I did not take it seriously I would not have done what I have done.'* Gary (CF)

*'My point is why tell people what they can or can't do things when they actually don't know about it. Everybody is different in my view and deal with things in their own way. I suppose if you look at it from their point of view they have a certain right to keep you right with your health. But they can't say you can't do that because it's going to affect your health this way and what not. I don't think they should be preaching to you about what you should or shouldn't do. But they have got a right to inform you if they could be any difficulties but you could always overcome that'* Oliver (D)

*'I usually get a lecture about my control'* Diane (D)

*'It was rather, I prescribed you that medication and now you don't want to take it, how dare you. I am your doctor I know better than you. I have been to university for 5 years and studied this that and the next thing. I know it sounds harsh. It is like any sort of tablet that you get from the doctors they just say right there you go. They don't say, if you take this you could get a slight nausea, Ibuprofen you can get quite a stomach ache if you don't stop it. They go, there you go it will cure you. Wonderful (sarcastic voice).'* Jackie (JIA)

Those with cystic fibrosis seemed exceptionally sensitive to being treated as a patient rather than a person with an illness. This viewpoint corresponded to feelings of self-definition mentioned previously and the notion of being 'normal' (albeit with a long-term condition) and how others sometimes see them (as being essentially different). The dichotomy between normality and difference was perceived to be entrenched within the health care system and the ethos it espoused. This finding may also reflect the frequency with which those with cystic fibrosis came into contact with health professionals compared to many of the others in the sample.

*'Quite frankly there is no more depressing experience than going to the outpatient clinic because they remind you of your fallibility and that you are not a normal person and that you have got respiratory problems and that your lung function is 40% of what it should be and all these other, and you are like, do you want to drive me into depression, you are going*

*about it the right way and they are doing it for all the right reasons but it actually has an adverse effect.' Quinn (CF)*

*'The only thing are the clinic meetings for CF. I find if I go too often I get too focused on CF and I do not like that. You can get addicted you know to talking to others with CF about people and how they deal with the same issues that you have got. But it can take over your mind a bit so I try not to do that. The staff are nice but you know it's just all CF.' Yvonne (CF)*

*'I remember the first time going to clinic, my husband has a particular dislike for one of the nurses at the hospital just because I think she was, because I do not see myself as a typical CF patient and I think she was just saying you know the routine thing that she says to everyone and I just happened to say obviously in my job I travel a lot and she said oh you would have to do a fit for flight assessment and you may not be able to do it and as I go to the gym she said don't go into the sauna or steam room, will you.' Ursula (CF)*

Complaints were also made (particularly against the medical profession) about some of the advice given by health professionals that was either unwarranted or felt to be inappropriate. These typically concerned judgements made and information offered about lifestyle changes. In part, the comments may reflect a somewhat defensive position on part of certain respondents but they could also indicate the types of approach adopted by some health care staff. The advice recalled was often dogmatic and unqualified in nature, facts presented rather than suggestions proposed. Even when asked directly, few said that they had received explicit information that had been specifically tailored to their circumstances on how to improve health. It was this attitude that induced the most resentment.

*'The doctors will say do not drink but she should be saying if you want to go out and have a curry and have a drink, just think about your blood sugar. She said, you should not smoke as it will kill you, I do not smoke but I have been known to have a cigarette on occasions. I think you get one shot at life. You want to achieve and get what you want in life and you cannot let being a diabetic control you, you have to control the diabetes. It has never gone wrong for me in all the years I've been diabetic.' Colin (D)*

*'The worse thing was that I smoked as far as he was concerned and I didn't weigh as much then but I do remember him saying to me I'm not worried about your weight but you need to stop smoking because it's affecting your joints, not my lungs or anywhere else but they're*

*affecting your cartilage and I remember asking him about diet explicitly and he said, no no, never mind any of that nonsense, just stop smoking and take ibuprofen' Sarah (JIA)*

*'One of them (a doctor) ended up telling me I was fat which I found really annoying and er I didn't appreciate that at all in the slightest and ...they didn't seem to want to give me care or help or advice as to how to change things. They just sat around and went errrr, you need to do this, you're fat, you need to lose weight by 2 stone. Give me advice and help on how to do that and I will.' Anna (D)*

Respondents did occasionally suggest practical ideas for how health services for people with chronic illness could be improved. One was for staff to better empathise with people's predicaments and be more courteous in manner, another was to do with honesty. Some individuals felt that health professionals were not always sufficiently careful about the limits of the medical knowledge they conveyed. In addition, those with co-morbid illnesses often spoke of their need for a more generalist approach to management, a system that enabled assessment and treatment to be united under a larger umbrella.

*'I suppose just to have a better understanding, to listen to the patients better, just find a better way, the way they deal with patients, just the manner I mean I know it's a hard job, know they're doing this every day but you must choose to do that job, that's the thing with doing nursing and things like that, you should want to help that person at the end of the day so you'll looking to help them so you have to relate to the way they are in their life at that time so you have to understand what's going on in their life and understand how their life's going, if that person's being shy and not saying so much about their life you have to find a way to get them to open up to you because you have to give them your trust at the end of the day and that's should be the doctor's philosophy on how to deal with people but I just don't see that in there, I see more well this is what you've got to do and that .' Peter (D)*

*'I suppose the point is here is that I tend to think when people make an awful lot of predictions about your health and when you suffer from a serious illness or a prolonged illness and um it may affect your eyesight and it may do this and it may do, they make all kinds of jumps and leaps and a half of them never come true and then these other things happen to you like problems with my colitis that nobody predicted, nobody told me when they put me on all these high dose antibiotics that I might end up with colitis and I might end up with other inflammatory problems.' Sarah (JIA)*

*'I feel I need a bit more of a personal, I need someone to go into my whole medical thing work with me for a while and get right into everything and you can't get that much attention when you are just seeing specialist about your knee for 10 minutes.'* Iain (JIA)

Numerous expressions of dissatisfaction were made by respondents about health services and the types of care received. Encounters with exemplar staff were felt to be the exception rather than the norm. Professionals who were perceived as knowledgeable, courteous and empathetic stood out in contrast to the dismissive and prescriptive approach adopted by many others. Adhering absolutely to recommended treatments and standardised protocols was simply not seen to be consistent with the day-to-day reality of lives as experienced. Engaging in unhealthy behaviours such as drinking alcohol, eating irregularly or unsuitably, and missing medication, for example, were regarded as inevitable and unavoidable consequences of everyday living. Advice therefore which did not take these individualised circumstances into account was much more likely to be criticised and disregarded (see comments by Oliver, Jackie and Colin on p. 159, 159 and 160 respectively). This attitude reflected the tension between self-care decision-making on the part of respondents which was grounded in their social and work-related activities and the apparent tendency of health care staff to over-prescribe rigid, inflexible programmes of treatment.

A further area of complaint from respondents was the perception that professionals at outpatient clinics often viewed symptoms of illness, such as high blood sugar levels, painful joints, low weight etc, as failure to comply with prescribed medication. Whilst these young adults often modified their treatment protocols, there was no evidence from their accounts that they were uninformed or irresponsible in decision-making about their health. As Jackie revealed (p. 143) her decision to stop treatment was taken because of her concern over side effects rather than ignorance about the benefits of a particular drug. Associated with this viewpoint was the allegation that staff rarely gave credit to the strategies adopted by individuals themselves to achieve a better quality of life (see Gary's quote on p. 159 as an example). In addition, according to these reports,



health improvement interventions were generally not provided by health professionals. Any advice on lifestyle change seemed to have been delivered didactically, such as lose weight, stop smoking etc, rather than in ways that supported people in making healthier choices about smoking, food, alcohol and so on.

Those with co-morbid conditions perceived the organisation of health care to be too focused on specific disease frameworks. A third of these young adults experienced (like many other people with chronic illness) multiple health problems, some of which fell outside their particular disease speciality. The lack of co-ordination across health service directorates made it difficult for some to obtain precise diagnostic and/or prognostic predictions or definitive plans for management. In these cases, individuals felt isolated in coping with their condition which led to a questioning of professional competence and a frustration with staff, who had failed in their view, to fully understand their predicament.

## **5.12 Conclusion**

There was a remarkable degree of consensus in how symptoms of illness were experienced and managed among these young adults from three different disease groups. All had grown up with a diagnosis of a long-term condition from childhood. Disease-specific issues were encountered but the main differences among the sample seemed to be due to factors such as perceived severity of disorder, gender and social and psychological impact on self. Perhaps as expected for this age-group, respondents appeared knowledgeable about their health status and possible complications of their condition and their approach to care reflected this standpoint. Decisions made about the amount, timing and types of treatment revealed respondents' views of themselves as competent individuals who knew what best suited their particular needs and circumstances. Most of these young adults did not acknowledge direct support from either close family members or patient organisations, except in the most functional



ways. Management of illness was largely taken-for-granted and perceived only as intrusive by those with deteriorating health. There was a widespread refusal to adopt an illness identity and no more than four respondents referred to themselves as disabled. Several criticisms were made of health services which centred mainly on the lack of fit between professional advice and individuals' decision-making about illness which was located in the social fabric of day-to-day activities. The organisation and management of care for chronic disease was felt to be wanting in certain cases and calls were made for a more integrated system of assessment and treatment.

In the sample, treatment of illness was largely undertaken informally by participants themselves. Many discussed a variety of strategies they used to monitor health status and control symptoms. In accounts of condition management, participants reported how they were able to exercise agency in ways that were often denied them by health professionals or as children growing up with illness. The next chapter explores how the young adults fared in the labour market as an adult and the meanings they ascribed to their experiences of employment along the way. The differences among participants became more manifest when they discussed their work status and their attitudes towards working lives. Descriptions of employment histories exposed the social divisions between participants and highlighted how personal circumstances could facilitate or impede individual motivation and the desire to work. The capacity to maintain working lives appeared to be dependent not just on health status but on opportunity, social background, educational experience and family expectation.

## 6: YOUNG ADULTS' EXPERIENCES OF EMPLOYMENT

### 6.1 Introduction

This chapter explores the attitudes of the sample towards work and career prospects and the issues associated with disclosure of illness and perceived discrimination. Respondents were at different stages of the employment process; some had not entered mainstream work, others were well into their career and a few were on incapacity or other disability-related benefits (see Table 4 on p. 171 for employment status of all respondents). The narratives about their experiences reflect differences between the young adults with regard to educational background and attainment, types of jobs available to them and the actual and perceived impact of illness on day-to-day activities.

As in the previous chapter, data analysis of themes is presented chronologically to reflect the temporal nature of events affecting participants during their lifecourse. As such, accounts about participants' experiences of career advice and factors influencing job choice come before the employment status of the sample and issues associated with maintaining working lives. In this chapter differences among the sample become more marked. This difference is reflective not only of disease severity but of the capacity of individuals to overcome the structural barriers of their social background. Respondents experienced different types of employment trajectories depending on their age, health status, expectations of their family and their educational qualifications.

### 6.2 *'I felt let down, they should have told me that': the perceived value of careers advice*

Most respondents recalled receiving some careers advice at school (number = 24) but this was largely felt to be unhelpful and very often irrelevant to their situation. It was presumed that careers officers would have known about their health status from school

records but no one recollected having been given pertinent information tailored individually to themselves. Whilst on the one hand, this might be seen as a positive action in as much as respondents had not been singled out on account of their diagnosis, on the other, advice was often provided that was of poor quality and which could, on occasions, be detrimental.

*'Er the truth is I was told that people like me got jobs in the factory and that er applying to go to college because university was never even mentioned, it was technical colleges then that a couple of my friends did, a very small group of people did that and most people did just get a job in the factory and I did get a job in the factory when I was 16, I did leave school and go and get a job in the factory, the week after I turned 16 but within about 3 months, I was very clear that I didn't want to stay there and through protracted negotiations I got back into school by sitting and passing my final year exams...The careers guidance person who we did have in 5th year was very clear that I would go back to working in a factory em partly because of my absences through primary school which she was aware of.'* Sarah (JIA)

*'I'd always wanted to be a police officer, my father was a police officer. I did not know at that time that they would not employ people with diabetes so I chose all my subjects, I sat down and talked to a guidance teacher and she told me what would be good and I chose all the subjects that would be relevant. Once I had done all that, I thought this is it, you just have to do that for the next 4 years I think it was. But in the end it was completely useless to me as I was told afterwards...(I found out) after the summer holidays when I was about 13 that this couldn't happen... I felt let down because they should have told me all that, they should have researched everything. They should have researched to give me the best advice and not just guess. Those people let me down and after that, I just didn't bother to try.'* Oliver (D)

Careers advisers were felt to have their own agenda or to be overly concerned with academic pursuits rather than providing specialist help.

*'I went to the careers adviser as normal but the guy was mostly interested in telling me to stay on and do more and do some 6 year studies or aim for something so that I could do this university course, asking me what I was interested in university wise but I basically had a feeling from the start that I did not want to go to university, I wanted to work straight away'* Iain (JIA)

According to these accounts, no specialist careers guidance had been available to respondents at school. Those who had attended higher educational institutions had also not sought advice about future job prospects from their university. This lack of

constructive input about employment for these groups of people is of particular concern. From narrative accounts, it would appear that in school settings, some career advisors, like teachers, may be making unnecessarily pessimistic assumptions about the educational attainment or types of work that could be achieved by those with longstanding illness. These individuals already faced restricted access to employment because of health status consequently effective guidance at an early stage could have widened the scope of opportunities available to them or at the very least facilitated their entry into some type of training, employment or higher education.

Policy is currently being introduced to address some of these issues. The UK government has recently produced a Framework for Vocational Rehabilitation (DWP, 2004) that seeks to tackle some of the barriers and obstacles preventing individuals with illness or impairment from gaining or remaining in employment. Also, whilst those with chronic illness including diabetes used to be debarred automatically from becoming officers in the armed forces, police and fire brigade services, the Disability Rights Commission has recently placed a duty on all public bodies, including police authorities, to promote equality of opportunity between disabled people and others (diabetes has been interpreted in this instance as a disability (DRC et al., 2006). For example, the police force now recommends that individuals with diabetes (and presumably those with other long-term conditions) should disclose details of clinical diagnoses with the confidence that a decision over employment will be made based on a fair assessment of medical, social and work-related factors (DRC et al., 2006).

### **6.3 'It was never something I was definitely going to do but something that I thought I'd enjoy': Factors affecting career choice**

Decisions made by respondents about work and career options were largely carried out independently from formal support networks. According to narratives, some had already thought about the types of job they wished to undertake whilst at school. Others were still unsure about which career path to go down well into their twenties. This deferment of decision-making about employment occurred among respondents from all disease groups by both sexes. Health status had some effect on choice of career either because of potential options being denied to respondents or because of lack of educational attainment through childhood ill-health. Approximately half the sample talked about having considered jobs in relation to their condition at some stage.

*'I had already made my mind up by then that I wanted to do nursing. The only thing that changed was that I'd been thinking in the back of my mind that I would have liked to joined the armed forces but because you're diabetic, it was not even an option...it was never something I was definitely going to do but something that I thought I'd enjoy, that type of thing, so I don't think I was hugely disappointed but it was just an option I could never consider.'* Beth (D)

*'At early high school I thought about being a lawyer but then after 5th year the results I was getting, I knew that was not going to happen and I thought well I always thought that music would be my back-up and I wanted to go and do that but 6th year at school was even worse than 5th year was and I did not have any of the exams that I sat, it just was a really, really bad year. I remember countless times being carried home from school.'* Andrew (JIA)

The perceived impact of child-onset disease on career choice, however, was somewhat surprising. Most individuals spoke of their diagnosis having initially challenged first thoughts of preferred occupation or career prospects. Once forgone, though, these early hopes were not inevitably mourned for at a later stage. As an adult, restricted career options tended to be accepted in this sample as an inevitable effect of illness. Respondents at interview invariably focused on what had been achieved or what could be rather than what might have been. Their narratives in this way seemed somewhat

reminiscent of Williams' (1984) sample of older adults with arthritis (cited earlier in Chapter 2) in terms of how past experiences appeared to be adapted and adjusted in order to present meaningful trajectories for the future. For these young adults, dwelling on something that could not be changed was futile and potentially damaging to self.

*'I was actually going into the Army to be a mechanic, to do the mechanics in the army. So instead of going into the army I have just gone on and done mechanics with other companies...So it had not actually affected the job I wanted to do' Theo (JIA)*

*'I have an idea about going into the teaching profession and I don't see why that (being diabetic) should hold me back in any way, apart from driving mini buses. I think that is the only thing that has gone through my mind that I would not be able to do it because of the current laws and regulations because there is a funny deal with driving licenses as you have to have it renewed every two years...' Hugh (D)*

*'I really wanted to be a volcanologist to start off with studying volcanoes and glaciers but I couldn't really do that with my CF but it was not practical anyway, even without CF it wouldn't have happened.' Yvonne (CF)*

Living with the effects of illness throughout childhood had some impact on choice of career but lack of educational attainment appeared more influential than restricted career choice in decisions made about employment among these groups of respondents. Entry into work was not always a straightforward process. Some respondents reported months of unemployment before obtaining work, others had a variety of jobs before settling into a more defined type of vocation, still more were at the point of negotiating gateways into the labour market. Five were not at work when interviewed and their experiences are discussed later in the chapter.

## **6.4 How employment was obtained**

Respondents reported using a variety of strategies to gain employment. For the most part, jobs had been secured by responses made to advertisements placed in the local or

national press. Other avenues included taking up trade apprenticeship schemes seen at job centres and one reported gaining work through the Pathway to Work scheme. In general, the New Deal arrangements were not well known amongst this sample although most were already in paid work (see Table 4 on p. 171 for employment status of respondents). However, two respondents with cystic fibrosis at interview mentioned that they had been contacted by personal advisers (presumably from some kind of welfare to work initiative) to discuss future work prospects although these were at a very early stage in the process.

Four in the sample, had secured a job through the influence of friends or family members. This type of entry into work, however, raises several issues. First, it may reflect the difficulty in obtaining employment for these types of individuals through the usual, formal channels. Secondly, whilst the use of personal connections can expand the range of possible opportunities for employment among these groups, it might also complicate the social and employment-related obligations that result from such agreements. Thirdly, this strategy is only available to those with access to wide personal networks, that is those who have high social capital. Finally, this informal entry into work obscures the multiple disadvantages often faced by people with chronic illness, in particular the matter of disclosure of health status to prospective employers and the notion that paid work is a relative aspiration. Accepting a job for its own sake was not necessarily an objective for many of the respondents in this sample.

The extent of personal networks available to participants broadened the opportunities available to them both in terms of friendship groups and wider social contacts. Those in the sample who had entered higher education or had accessed employment through large organisations had much greater possibility to progress their careers and to make influential links. It was notable that the individuals who were not in paid work (see



also section 6.6.3) had fewer networks or resources to access which profoundly affected the outcome of their circumstances at the point of interview.

**Table 4: Employment status of study respondents at point of interview**

	Cystic Fibrosis		Diabetes (Type 1)		Juvenile Idiopathic Arthritis	
	Males	Females	Males	Females	Males	Females
Number in full-time work	2	2	4	4	4	4
Number in part-time work	0	2	0	0	0	0
Number in full-time education	0	0	1	1	1	0
Number out of work	3	1	0	0	0	1
Total	5	5	5	5	5	5

### **6.5 ‘Do I tell them, if I tell them, how do I tell them’: the issue of disclosure of health status**

This theme was important throughout the narratives and encompassed how information about health status was revealed in all social arenas not just in relation to employment matters. This section, however, focuses mainly on the control of personal data about health status to prospective and present employers, work colleagues and the timing and circumstances of such announcements. Half the sample claimed to pursue a policy of open disclosure about their condition at the point of applying for a job or place at university. This practice did not appear to be associated with gender, disease group or any particular type of employer although was understandably influenced by visibility of impairment. For those who chose to disclose, being honest at an early stage of application was perceived to confer certain benefits. A few felt that revealing their health status could actually help them secure work and was felt to be particularly advantageous in gaining entry into further education.

*'I wanted to give it a try and the teacher said well there's no harm in trying because I'd explained it about my situation really, being in and out of hospital, that's probably why he gave me a chance and then I said I really love art and want to give it a try' Eddie (CF)*  
(Talking about his application to Further Education College)

*'I thought well mebbe they'll think oh they've got someone with a disability then it'll make it look good for us, so I thought I'd mebbe get the job for that reason, it could go either way, I thought' Ruth (CF)* (Talking about her application for a job as a shop assistant)

For some respondents, particularly those with diabetes, self-disclosure seemed to be more about a health and safety issue. Informing employers and work colleagues of their need for regular medication served to reassure these individuals that they were minimising risks to themselves and others caused by their diagnosis.

*'I usually tell them. I drive a forklift all the time and you cannot continue doing that if you are having a hypo. You have people's lives there. You are lifting huge bits of steel that weigh at least a ton if you drop that on someone that's going to kill them. You cannot afford for that to happen so you have to say to them look I am taking the time out, I have to sort this out and if I don't someone is going to get hurt' Oliver (D)*

*'Normally I don't bother saying anything because it does not really bother me at it is well controlled so it does not really make a difference but because one time I never told them and then I ended up mentioning it for some reason and they said oh you should have told us before. So I just make a point of telling them now.' Nicola (D)*

Occasionally, respondents in the diabetic group also expressed the view that it was an employer's right to know about the health status of potential employees. Aspects or consequences of illness, such as the potential for hypoglycaemic attacks and frequency of sick absences, however, were likely to have been deliberately played down or made light of in discussions with prospective line managers. A perception of possible discrimination through employment was very evident throughout the narratives of all these young people.

*'I am a very honest person and if you are going for an interview somewhere then I would want whoever it is I would want them to know that I am a diabetic. But I think most of these people ask anyway. I would never conceal the fact because then it's just a recipe for disaster.' Colin (D)*

*'I mean in this job, they came to ask me when I told them what diabetes I had so it wasn't like I was telling the nurse, I mean I was telling my boss and he say oh right I mean because I'm well controlled and everything so that's the thing I mean fair enough if you're off sick all the time and your blood sugars, I could see why people wouldn't give you a job because you're not going to be working and you're going to be a liability to them.'* Peter (D)

Revealing a health condition to future employers was also likely to occur if respondents felt they would not face discriminatory action because of it. Those who had secured work through family members or friends, for example, were more adamant about the need for full disclosure at an early stage in the employment process. For these people, however, employers' knowledge about health status would unlikely prove problematic. Others who were more confident of a 'clean' health record could also afford the luxury of being more open.

*'I think you have to tell them. I've never ever had a day off my work because of it (arthritis) but just in case something does happen they need to know that. I think if I was off sick a lot with it then I probably would not have told them about it but because I've never had a day off and I can go in there and say look I have arthritis but I've had it for how ever long and it has never, I do get sore at my work but I've never ever been off because of it.'* Bryony (JIA)

Disclosure, however, was not an absolute concept for these respondents. At least eleven people reported some type of partial concealment of health status on applying for a job or during employment. This reluctance towards total disclosure took several forms. Sometimes, it was associated with timing whereby self-disclosure would take place but only when employment had been gained or when individuals had little choice but be up-front about their condition.

*'I went through the motions in my head of do I tell them, if I did tell them, how do I tell them. But I think it was partly because the job at Bladons, I really, really wanted. I did not want to give them an excuse not to employ me...I didn't tell them at my interview, I told (my line manager) on my second day, I actually think it was because I thought I had lost a pill box in the office. I'm never normally careless with that sort of stuff but I think I didn't put it in my pocket that day. I normally carry 2 pills boxes. Just creon that's in there and I put my hand in my pocket and there was only one and I wondered what I'd done. I actually found it at home 2 days later. I thought well if somebody picks up a packet of pills in the office, I need to speak to someone and just tell them well actually. That was the*

*second day or something so that was the driver but they were like so what, you can still do your job, it doesn't matter. I felt better having got it out in the open' Quinn (CF)*

*'I didn't tell them, I thought they wouldn't take me on, The first time I had to come into hospital that is when I told her (immediate boss) and they were all right about it. I worked for a year with them.' Fred (CF)*

For the most part, respondents who dissembled practised on a 'need to know' basis particularly in the early stages of securing work. Mike's description of how he came by his employment is a good example of this type of strategy. Individuals said they would not lie about their condition but neither would they volunteer information that might be detrimental to them in the workplace.

*'You see the thing is they have these forms for employers to try and stop them being discriminative but they still can be. They are really stupid because they only put on it have you been in hospital in the last 5 months or have you done this for the last few weeks or have you seen a doctor for your health in the last year. I just said yes because it was true. After they said I had got the job they said because I had ticked yes I had to go and see a doctor for a medical. That doctor never asked what was wrong with me either. He said what did you see a doctor for I said I had a chest infection. Again not a lie, I did not see the point of me saying oh by the way I have had a lung transplant, it would have just given them the frightners. The doctor would go, oh shit and he would go oh no, he is no good, he is not well enough. GPs and all the general doctors do not really know a lot about CF so I thought no I will just tell them the truth and if they want any more information out of me they will have to ask more intelligent questions and they didn't.' Mike (CF)*

This type of circumlocution used by individuals to gain entry into work recalls Admi's (Admi, 1995) research on disclosure of CF who found that information management in chronic illness is a contextual and controlled process. Disclosing health status rarely appeared to be a personal issue for respondents in this sample, rather it was the perceived effect of how others, in this case, employers, might deal with the knowledge given to them that influenced the outcome itself. Five respondents, three with more severe forms of chronic illness, spoke of having changed their position on disclosure throughout the course of their employment histories. In all cases, the shift was towards concealment of health status when going for a job. Two of these individuals felt that

their previous strategy of open acknowledgement may have stopped them from obtaining work in the past.

*'There was one interview I went to and I thought I had answered their questions all right, I was not going to mention my arthritis as I thought it should not have any bearing on what I am going to be doing. And as I was going down the stairs I actually said to her I did not mention this in the interview but I have arthritis I said it does not bother me, all I need is maybe a day off every six months to go and see a doctor she said oh right and I thought oh I made a big booboo saying that to her.'* Jackie (JIA)

*'I had had this year's experience teaching in school and I thought the council all over the country were looking for a sort of classroom teacher and I applied for hundreds of jobs, they have an anti discrimination policy where if you disclose a disability and you meet the minimum requirements for the job, you get an interview. But they did discriminate, there was one I phoned back, it was Caledonian High School and I asked to speak to the person and I was told I did not have enough secretarial experience which I thought was bollocks...They said we do not think you meet the requirements for the job and I asked about the anti discrimination policy and they said that is only in effect if you meet the minimum requirements. I said that as far as I could see from your job description and requirements I meet that and all you are doing is blatant discrimination and I wrote to the council and they wrote back saying that they felt that all these things had been done properly but they have a very bad reputation for that sort of thing and I felt for months and months I was just fighting against a brick wall.'* Colin (JIA)

Another respondent felt that his encounter with an occupational health assessment had been overly bureaucratic and this experience had discouraged him from further acts of disclosure in the future.

*'I did put it on my form and that meant that I got an occupational health assessment and the occupational health assessment pushed me back from actually, well I never actually got to the stage of being interviewed because I had to go on a queue for the occupational health and then once I'd been done for that I couldn't actually go for my interview and so I never actually got into nurse banking so that's my experience. I mean I suppose it wasn't their fault because I'd put it down and when I went along, the occupational health people could see that I was fine but they had to do testing and it just seemed like a waste of time when, as far as I'm concerned, I'm quite capable but I suppose that would be the main reason I no longer put it down'* Xavier (JIA)

Three respondents (all with arthritis) reported that they had never revealed their health condition to potential employers. For these individuals, having a chronic condition was simply not perceived as relevant to their ability to undertake work. Their motivation to conceal was also prompted by fears of potential discrimination or prejudice by employers.

*'At interview I was asked about health problems and at the time, I was not sore at the time so I really said no I've not had anything so I suppose I have told a little white lie sometimes when I went to get jobs but it's just to get a job and once I have the job I then get to prove myself'* Theo (JIA)

*'Partly I don't feel it's their business and a bigger part of me thinks they would probably judge me because the other thing is to be honest with you some contracts are short and if they think you're going to be off sick for periods of time there's no way they'd give you the job no matter what rules and regulations say about not discriminating against people. If I knew I was employing somebody who was likely to be off sick for 3 weeks in a six month contract I would really have a hard time with that and I don't think they're any different to me at all'* Sarah (JIA)

*'The reason I never told that employer was just because I mean there might have been two of us exactly the same and he might have thought well he's a bit of a liability because he's got arthritis in his knees which I mean if you're a joiner you're on your knees a lot and up and down stairs and bending down and everything.'* Will (JIA)

Once employment has been secured, most respondents adopted a strategy of at least partial disclosure about their condition to immediate line managers and/or trusted work colleagues. For some, revealing a health condition helped them access support in the workplace particularly for managing sickness absences from work.

*'They always looked after you and they were quite happy about hospital appointments and things like that and obviously because I have CF most big companies will have a limit for sick days but for me they were obviously not going to worry about the limit if I reached it or they were not going to question anything because they knew that I may be ill more often. So that was their way of looking at it. It was not a problem to them.'* Lara (CF)

*'We get a bonus and a salary rise every year in November. Sickness is counted against you. But because of the amount of fuss I have been making my boss is clear on the fact that although I was off for so many periods because of this (arthritis) and it's something that I*



*can't help, he shouldn't be penalising me for that, but they will no go back on that but as far as it is between me and my manager she says she's aware of why I'm off and she's not going to penalise me for it.' Iain (J1A)*

Respondents, however, tended to control the amount of information they disclosed to others at work. Sometimes, disclosure was used to account for symptoms of illness (such as cough or stiffness of joints or the need to eat regularly), at other times these symptoms were given other explanations. Managing illness in this way reflected the personal but not necessarily private nature that chronic illness had for these individuals. The ways respondents seemed to purposely choose what, when and how to reveal information to employers and work colleagues reinforces Admi's (1995) findings that sharing health details among those with chronic illness is a discretionary and regulated process (see also Chapter 2).

*'I don't want to chat to people about it but if I'm sore I will say I 'm sore or I'll tell them when I have been to hospital what he says or things like that but it's not something that I feel I have to keep banging on about all the time.' Bryony (J1A)*

*'Most of the time I'll not go into it and I'll not bother to explain stuff and maybe just say it, sometimes I'll just say I done my knee damage years ago and it still plays up I'll just say something like that, if I know it's not too important, I'll still tell somebody all about it if they want, if I know them.' Iain (J1A)*

*'Sometimes people say oh have you got a cold, no I don't actually if it's not the time or not the sort of person that you talk to but if it's people that you work with, I feel obliged to tell them as they're the ones who'll have to work with me and if I'm having a coughing day they're the ones who are going to listen to my cough and I know how annoying it can be for other people if you are sitting and someone is coughing away and...So I do explain to those that are working closely beside me about what I've got and how it affects me' Lara (CF)*

Disclosure in the workplace emerged as a complex issue. A variety of strategies was adopted by respondents ranging from full, open admission of one's condition through partial cover-up to complete concealment from employers about health status. Visibility of symptoms, types of work undertaken and perceived effect on one's employability played a part in the approach taken by individuals at any given time.



Some respondents claimed to always operate in a consistent manner in terms of either full disclosure or full concealment. For most, however (see Quinn's quote on p. 173 as an example), context was key whereby circumstances such as the need or desire for a particular job influenced how individuals would respond with respect to disclosure. Once secure in employment, the majority tended to reveal some or all aspects of their health status over time to employers and close colleagues at work.

## **6.6 Working status of respondents**

At the point of interview, twenty respondents were in full-time work, two worked part-time, three attended higher educational institutions and five were not working and received full disability-related benefits. This section describes the circumstances of how some of these individuals negotiated the various pathways of the labour market.

### **6.6.1 Full-time working**

Twenty respondents reported working full-time. A further three attended university (two male, one female) and all these had taken up temporary or part-time work at some stage previously. There were no obvious patterns between types of work undertaken (or entry into these jobs) among respondents with different illnesses. Women, however, were more likely in this sample to have a degree (females = seven; males = one) and perhaps as a consequence there were more females employed in professional or technical occupations than males (See Table 5).

**Table 5: Types of employment of study respondents**

Type of work	Cystic Fibrosis	Diabetes (Type 1)	Juvenile Idiopathic Arthritis
<b>Professional</b> (such as nurse, marketing officer, own business)	Female = 1 Male = 1	Female = 2 Male = 1	Female = 0 Male = 0
<b>Technical</b> (such as computer technician, mortgage advisor)	Female = 2 Male = 1	Female = 2 Male = 0	Female = 2 Male = 1
<b>Trade</b> (such as joiner, mechanic)	Female = 0 Male = 0	Female = 0 Male = 2	Female = 0 Male = 2
<b>Manual</b> (such as shop assistant, warehouse person, labourer)	Female = 1 Male = 0	Female = 0 Male = 1	Female = 2 Male = 1
<b>Status of other respondents</b>	4 (1 female, 3 males) on disability benefit	2 (1 female, 1 male) full-time at university	1 female on disability benefit 1 male full-time at university

It was sometimes difficult to obtain a coherent employment history from respondents, some of whom had changed jobs several times since leaving school. Equally, respondents varied within and between their disease groups in terms of reported duration of employment. Females were generally more likely than males in the sample to have stayed with the same employer for years rather than months but this gender difference was not marked.

Being in full-time work was a conscious decision for many respondents. Going down the part-time route was only referred to by the women in the sample who had already reduced their working hours. Changing jobs was regarded as a means to career progression; health status being one factor to take into account when seeking new work but was by no means of over-riding importance to the majority of these individuals. No one said that they would stay in employment simply because they would be unlikely to secure other work. The age of this sample may have influenced this perception and reported behaviour.

*'I always look at the jobs, but I like where I am and I enjoy it, it is usually a good laugh and you just meet different challenges and different things crop up.'* Lara (CF)

*'I am always looking for something that will pay me more, I'm 26 now and I need to get my act together basically and stop playing around so much'* Oliver (D)

*'I was with the first company and I decided I wanted to change so I went to this other company and the other company I fell out with the service manager so I went back to the original company. I'm actually quite fortunate because of my trade, mechanics and HGV mechanics are in quite a high demand there's a short supply of them. So in that sense it's quite easy to move about jobs as well.'* Theo (JIA)

### 6.6.2 Part-time working

The two women with CF who worked part-time had initially been employed on a full-time basis. One was a shop assistant and the other worked as a computer technician. For the latter, the decision to reduce working hours was instigated by her desire to devote more time for treatment and to have a better quality of life outside work. Her sister (also with a diagnosis of CF) worked flexibly and this factor seemed to have been a stimulus for Yvonne to try to negotiate part-time working with her employer.

*'I think I really got the idea because my sister works part-time and she said it was such a good thing. I have been thinking about it for a year or so, I just needed the courage to, my boss was quite against it to begin with as I'm basically in a support role and people phone up needing things done like now and it took several weeks for her to finally agree to a trial. To begin with she just told me I was talking rubbish because I was coughing less she thought I was fine but the reason I was coughing less was because I was doing my physio in the morning and she had a biased view. But I've been doing it for about 3 months now and I think she is going to agree to it. But she's not cut my pay yet which is good but I am sure she will soon.'* Yvonne (CF)

This reduction in work hours appears to have been reasonably successful at least on Yvonne's part but employers could potentially exploit the advantages of reduced hours in some cases. Ruth's description of how her status as a full-time employee changed to that of a part-timer showed that negotiations were not always handled tactfully.

*Helen: When did you decide that you wanted to reduce your hours?*

*Ruth (CF): Em in about the October or November (about 10 months before the interview)*

*Helen: How did that come about then?*

*Ruth (CF): My boss approached me actually, the new one who doesn't understand, em we got a new area manager so the manager for her he obviously looked at, I'd been off, within the 2 and ½ years I'd been there I'd had absences but there were never one offs, they were 2 weeks at a time to clear the infection so they're obviously thinking about their money and offered to reduce my hours, making it look like a favour to me but it turned out it was a favour because it makes my quality of life better really, I've got more time for myself. It was their choice but they tried to make the words come out of my mouth, it was like oh well you could do this if you want to like, talk me into it but it suited me anyway at the end of the day so. I was gonnae ask to reduce my hours again but only by about 5 hours so that would mean it would be about 4 hours a day and I wouldn't be entitled to a break and I think I'll need a break so I might as well do the 5 hours and get myself a tea break.'*

Female employees in low paid jobs seemed to be particularly vulnerable to insensitive treatment by employers. Vicky, for example, had applied to go part-time following a spell in hospital for a bad chest infection. Whilst this request was granted, she was required to work five days a week rather than the three she had originally asked for and also to do the same amount of work expected of a full-timer.

*'I did that for a wee while but it was still getting hard because although I had gone part time I still had to do full time work. So they did not cut down my work. I'd wanted to go 3 days but the boss would not allow that so I went in 5 days but I went in at 10 and left at 3 but I didn't get a lunch. I was going to stay until 4 and take a lunch but then the money situation would not have been any different. So it was 10 until 3 and that was it. I would take things in with me and keep it in my desk and nibble during the day but he hated people eating because when every people walked in we were the first person people could see.'* Vicky (CF)

Two months later, Vicky gave up work altogether. She appeared remarkably philosophical about her situation and unsurprised that she had not been treated more sympathetically. The bottom line, as she saw it, was that she was expendable; business needs automatically took priority over any 'special' treatment of staff.

*'And when I came back (from hospital) I did discuss it properly with Melanie. The boss was not a very people person so Melanie did the talking. You would get a good morning and a good night from him and if you did not do something properly he would tell Melanie and*

*Melanie would call whoever was wrong....At the end of the day it was his office and it was run professionally and I could not be a special case which is fair enough, it is his business.'*  
Vicky (CF)

Notably all those who had attempted to reduce working hours to better accommodate the health effects of their illness were women. Whilst my sample is small, it could be the case that females find it easier to request part-time working in the workplace and/or that it is more socially acceptable for women to be employed on this basis. None of the men in this study, for example, ever contemplated working less than full time even those who had given up their jobs or had been asked to leave because of high levels of sickness. Employment policy initiatives such as the New Deal provided some pressure on out of work respondents to take up some structured activity, either paid or voluntary work or attendance at college. It was perceived to be acceptable to undertake part-time further education course but not to look for work on a similar basis. It is likely that remaining eligible for full disability benefit was also a determining factor in this regard.

*'People said get a computer but technology is not my thing. I like to do labour outside like a labourer on a building site or something. I like all that stuff. Because you get to be with other guys but I am just not fit enough now or healthy enough to do that now. Plus all the dust. You have to think about the dust and the changes in the weather. So I have been thinking of going to college, you know that New Deal as long as you do not work for longer than 16 hours. I've been thinking about doing something at college. I might go up in the morning since I am staying here as it is just over the road and collect a prospectus to see what courses there is.'* Fred (CF)

*'I got a letter from New Deal. I don't know if you've heard of it, it's people, a company that help people with disabilities and people who have been away from work for years and they want to go back to it and they help them out to try and, it can take them months, and the agency tries to find the right job for you. I went down and had a meeting with them and I explained that I wanted to look for something but ...as to an actual job I don't know if I'd cope..., I'd hope they'd understand, so whenever I did go into hospital then they would accept it, you know, and I could come back to the job.'* Eddie (CF)

### 6.6.3 Unemployment

Of my sample of 30, five respondents (three males, two females) were not working at the point of interview and two of these (males, both with cystic fibrosis) had never been in continuous employment for more than three months. Two females had given up work because of ill health and one was on a waiting list for a double lung and heart transplant. All five were drawing Incapacity Benefit or Disability Living Allowance at the middle or high rates and their attitudes towards work were somewhat ambivalent. At the time of interview, all considered themselves unfit for work yet the prospect of a job was entertained by some at a future time. Work as an issue was rarely discussed in depth with hospital staff or GPs who were seen as having little authority in the field and who in fact rarely seemed to bring up the topic of employment with them. The decision to give up work then had been invariably taken by individuals themselves often without consultation with any health care professional or vocational rehabilitation officer.

*'If they (an employer) looked up and saw what CF is all about them sitting in front of a computer is no hassle at all but obviously it is for a mechanic or labourer, they would say well you are not the right person for the job which is probably true...I know myself that I couldnae do it...It would be too much for me like, aye too much like sometimes in the house I have to do the hoovering and that and I am going round the house with the hoover and I tire, sometimes I really do tire.'* Fred (CF)

*'I knew I was getting too tired with what I was doing. My Dad was trying to find me things to do that were not energetic but when he went to the hospital with me one time they said the best thing I ever did was give up work because my weight is going on properly and he just shut up after that.'* Vicky (CF)

Only one respondent reported talking to her hospital consultant about work-related problems who had been concerned that her job was having a detrimental effect on her health. Whilst there was agreement by both the individual and the doctor concerned that this work was too onerous to maintain, the timing of when to resign had been taken by the individual herself. She too had recognised that having no flexibility to

determine either the pace or schedule of work meant that she was faced with little option but to give up employment for good.

*'I did that office job for about 4 or 5 months and then Dr MacDonald said either give up work and rest or I will bring you in (to hospital) and rest. I said no it was too near Christmas I was not coming in. He said he would give me to January to think about it but I had to tell my employers, it was affecting my health I was getting up at 8 o'clock, no my Dad used to leave at 10 past 7 to miss most of the traffic although he did not officially start until 8.00 or 8.30 so he was in the office by 7.30. I could not drive at that time so I had to go with him and he had to pick me up at the office at 5.00 on the dot...It was too much for me'*  
Xanthe (JIA)

Those currently out of work described the jobs they had had and the activities they had found difficult. Most had received no support either formally or informally with work-related problems and few displayed any awareness of possible workplace adjustments and/or flexible working policies that could have been implemented. The jobs they described, however, were often low paid, contractual in nature or voluntary that offered little recourse to organisational networks or formalised employment policies. Being employed in these circumstances provided little room for possible intervention. As such, this type of work was perceived in a rather dichotomous way as jobs you were either fit for or not fit for.

*Fred (CF) 'My Dad got us a job in a hotel doing maintenance in Lothian Hotel in Liverpool Street. I couldnae do that, because the hotel had all those different coloured lights, I was getting roasted with the heat, everything was dry and all I was doing all day was coughing and I was going home and my headaches were killing me, I was knackered. Physically falling asleep but I couldnae fall asleep because my lungs were sore. I had to give that up and I haven't worked since and I dinnae think I'll ever work again*

*Helen: Why's that?*

*Fred (CF): When I was working doing the floors, Monday to Friday and I was just knackered, I was coming home and going to my bed. I would go to work in the morning and come home and fall asleep after my tea and then back up in the morning for my work. Weekends I was just sitting in because I had no energy...'*



*'I really just want to do something, you know. I even tried to do volunteer work for the NCDL you know, dog walking, National Canine Defence League, it was called that, I thought well I love animals, you know, I had a dog before and I said, well I like looking after dogs and I like going out walking, if you've got a well behaved dog, they just take themselves and if it's a nice sunny day and you go down the water and that, the dog can run about, I think that's brilliant so I said to myself, well I'll register with the NCDL but I, honestly, I couldnae even do that because the dog had been abused and that, it was like a rabid dog and they give me this big, massive Alsatian and it was jumping about and it was crazy, you had to keep him on a leash at all times and it was pulling me and dragging me through a swamp and I was getting really out of breath and I said I just can't go back to that because I was looking forward to doing that and it was volunteer work but I was just couldn't handle it.'*  
Eddie (CF)

In comparing the unemployment patterns of respondents across the three disease groups, those most obviously affected by their diagnosis and consequent health impairments had cystic fibrosis. Within this group, four were not working at interview and two (both females) had at some point negotiated part-time hours with their employer. Of interest is that the three unemployed males were from low socio-economic backgrounds and two of these had particularly turbulent home lives. Disease severity was obviously a factor influencing unemployment in these cases, yet it has also been shown that rates of unemployment are exceptionally high among those with CF from lower socio-economic groups (Walters et al., 1993). This sample was too small to make generalisations but it is possible that being male and undertaking manual work with a diagnosis of CF may not be conducive (as Gary and Fred found out) to securing or maintaining jobs for long periods.

*Gary (CF): I thought to myself I have always liked cars so...I spend days walking about Glasgow looking for a job. And I got so close to getting a job, a gaffer was going to take me on but the insurance company would not insure me. So that was bugged.*

*Helen: Did you tell them about your illness then?*

*Gary (CF): Yes. I had to I could not lie to them, I would be working underneath a car with machinery and that all day, and go and lift this wheel and that you know, so they needed to know.*

*Helen: So was it the employers' insurance that would not insure you?*

*Gary (CF): I think so. I didnae really go into it. I was just like disappointed because it would have been something good to have got into. It was a classic cars garage. It was not a big garage, about 6 cars but old cars. Would have been good to have got into because, the guy I saw really took to me. They tried their best.*

*'The first job I got was laying floors, I liked that. I worked for a year with them and I was off 18 weeks with CF. Then they said they had to let me go and they did not say why they just said there was no work. It might have been that there was no work but it might have been that I was off that many times.'* Fred (CF)

A related issue was the type and quality of jobs being sought and obtained. For these individuals, work was not necessarily perceived in itself as being a particularly worthwhile goal and when this factor was compounded by a lack of skills and chronic health problems then options open to them were limited. The only jobs available to Fred, Eddie and Gary were inevitably going to be low-waged with poor working conditions and few opportunities for promotion.

*'I'd like to work for myself because I don't want anybody telling me what to do. For at the end of the day for how ever long or short my life may be, it's my life. My mate Andy for example works at Centaur's, been there for 4 years since he left school. I watched him work for 2 years without a break not one night off and just a couple of weeks ago I saw him and he's still stacking shelves and pallets, you ken, that's not a job, that's just slave labour.'*  
Gary (CF)

## **6.7 Employment-related Benefits**

No one in the sample thought that receiving disability or unemployment benefit was in any sense a real substitute for working. The ordeal of applying for disability allowances was occasionally alluded to but some of the sample had never opted for benefits at all nor did they intend to.

*'There have certainly been periods where I probably should have been or could have been entitled to benefits but I'm glad I didn't go down that route. I don't like being reliant, it's a cycle, and I know why people do it, I do understand that and I know there are people who*

*physically can't work whether it's a mental or physical illness or work is too much.'* Sarah (JIA)

*'I've worked since I was 16. I don't think I'm disabled enough to get any benefits to be honest with you.'* Jackie (JIA)

*'I would never be able to rely on benefits because I'm not that ill.'* Lara (CF)

Those who did not receive benefits were occasionally begrudging of those who did. This occurred most often in discussions about free prescription charges. It was felt by some respondents who had cystic fibrosis that there were disparities in entitlement between different disease types. In the eyes of these individuals, it was anomalous that they had had to pay for medication while diabetics did not. No rationale was acceptable to them that might explain this incongruity in policy.

*'I've not got diabetes or anything like that to put me on the exempt list which I always feel, it costs enough for me but somebody who is on multiple medication it must be horrendous. CFs are not exempt which is ridiculous really when you think how bad some CFs are and how much medication they have to take. Diabetes oh right they need drugs too but they get them for free.'* Lara (CF)

*'I can at the end of the day afford an annual prescription but when that expires I leave it as long as possible before I renew it. But I am more frustrated at the fact that if I was a diabetic I would get it. Malcolm Chisholm was saying 80% of patients are exempt, I am going, I must be one of the 20% that is not. I depend upon prescriptions to survive to live. It should include CF and I am sure there may be other conditions that it would make much more sense to include.'* Quinn (CF)

Some who received disability allowances said that it helped them pay for additional costs of treatment, such as attendance at a gym, extra food and for home care. Having to rely entirely on benefits alone, however, was perceived to be difficult.

*'I get care money, so it's like money I can give to my mum and dad basically it's like dig money, I know that I'm able to still feed myself if I'm unwell, I wouldn't get a sickline to cover my work because OK now I've got that money but it's not like a back-up bank account, it's just there to encourage me to look after myself, that's the way I see it.'* Ruth (CF)

*'I get free money so I just take that. I didn't sponge off society all my days but I sponge off it now because I need to. But to be honest with you, we do not get enough, £500 a month, £600 a month and we should have a wee bit more than that.'* Gary (CF)

The work circumstances of these respondents throw up a number of issues.

Unsurprisingly, educational attainment offered individuals more options over different types of employment and, in addition, afforded them better opportunities to move from job to job if they wished. This seemed to be the case for those who had achieved qualifications of any sort not just those who had a degree. For example, the two male respondents with CF who had not obtained even standard grade levels had fewer choices and were unable to achieve a realistic job match to health status. Undertaking heavy manual work was patently not a suitable occupation for severely affected individuals with CF nor incidentally for those with arthritis. A gender difference arose with respect to part-time work in this group that seemed to favour women over men although there was little discussion in general within the interviews about the concept of flexible working. Perhaps the age of the sample affected more serious consideration of this issue.

Those who had lost their jobs or had given up work because of ill-health were matter-of-fact about their situation. Like Pinder's (1995) informants, they also did not see themselves as passive victims of malign forces. Rather, their situations reflected the experience of living with severe chronic illness within work environments that are not yet able to handle the ideals of workplace change. In spite of policies being introduced to promote equality at work for disabled people, organisations appear to predominantly rely on employees being either unequivocally fit or patently sick. Employees with long-term illness muddy the waters in this regard and expose the tensions at a structural level between specific and general inequalities within society. There is moreover a lack of clarity within government policy about the extent to which individuals should maintain working lives in the face of frequent episodes of illness. In

this sample at interview, respondents who were not at work often referred to themselves with respect to their circumstances as being too sick to undertake employment of any kind. Taking Vicky as an example, whilst her preferred working arrangements were not honoured by her employer in that she had opted to work three long rather than five short days per week, her decision to give up altogether was also predicated by her desire to maintain good health in advance of a transplant operation. The interplay therefore between agency and structure with regard to employment matters for these groups of people requires to be understood in relation to the complexity and relationship surrounding different needs.

### **6.8 'It's good to get out and mix with people and work with them': the value placed on working lives**

Work played an important part in the lives of the majority of these respondents. Apart from monetary reward, being employed provided a framework or structure to a week and kept people mentally and physically active. Perhaps more importantly, it also represented a link between oneself and the rest of society, a factor that was thought to preclude unhealthy introspection.

*'(Work) means I get out and speak to other people and meet people and help people and do my bit and you are part of something. I really like work, I enjoy it, it is usually a good laugh and you just meet different challenges and different things crop up. It can be quite interesting but it can be quite boring some of the times too.'* Lara (CF)

*'(Work) gives you structure, it stops you thinking about yourself and obsessing which you know is dangerous and it makes you realise that there are people with various problems and some more than yours in some ways and you're not some special case and I think just in terms of mental stimulation and engagement with the rest of the world that's important.'* Sarah (JIA)

Even when jobs were not felt to be interesting in themselves, they nevertheless fulfilled important social functions in offering opportunities for interaction and contact with people.

*'I think I would get really bored without it. The people are really nice and the social side. The work itself is not very exciting but I don't mind so much'* Yvonne (CF)

A working life also represented the prospect of demonstrating in public one's essential normality in relation to everyone else in society.

*'Everybody had got to do it and I do, it's good to get out and mix with people and work with them and I enjoy doing it. I like to get a career and earn a wee bit more money, buy a house, the usual kind of stuff. Just what everyone else does.'* Mike (CF)

Whilst work was intrinsically perceived as beneficial, many respondents often made a distinction between different types of jobs that they had either undertaken themselves or contemplated. Some work was regarded as more rewarding or worthwhile than others. This demarcation was not necessarily an obvious one such as between manual and professional occupations but seemed also to link to activities that served a valuable function or were felt to be of personal interest.

*'Work is in some ways, it is a means to an end and also the voluntary stuff that I have done, going into teaching working with kids, I would prefer to work where I actually got something out of it. Passing on knowledge or even in the catering trade.'* Andrew (JIA)

*'I have increased my confidence by doing this job and I feel more confident in dealing with their problems and the fact they look to me for help'* Nicola (D)

*'Well I like to work because I feel I have fun with the wee ones and they're funny too and they kind of bond to you as well as you bond to them and I love going to work because it's great to see how they are grow up and how they achieve in life and things and what they gonnae go on to do.'* Kate (JIA)

There were no apparent differences in career mindedness according to gender or disease type. Females with arthritis or cystic fibrosis were just as likely as men with diabetes to be ambitious about their job and career prospects. However, individual characteristics did exist and employment aspirations varied across the sample. Some

admitted to having very few career inclinations; others desired to get ahead and become successful in their chosen occupations.

*'If the opportunity arises, I will go for promotion. I do not intent to stay at the bottom because I get bored easily, I need to keep challenged and things like that. If there are opportunities I will go for them and Jean knows that so does the big boss she knows that as well. I know there are people who are happy to stay at the bottom but I am by myself so I have to think about for me to buy a house and me to be able to keep myself in the manner that I would like to be accustomed. I have to earn more money so I have to try for promotions and things like that.'* Lara (CF)

*'I think I just want a simple job but I'm quite comfortable where I am because I know the ins and outs and I wouldn't really have to think so I think it's basically a comfort thing to stay there for me as well because I can't be bothered doing anything else anyway.'* Ruth (CF)

*'Basically I have big aims like I really want to, the way I am just now with (my company) I am looking to get them to pay me to do exams, financial exams so that I can become a financial advisor by myself, an independent one, and then start up my own business. So that is basically my long term plan so I do want to do well in the work, I do want to make a good impression, I want to get on. The better work you do the more chances you get, so I am really driven about my career.'* Iain (JIA)

Disease severity played a part in actual employment but did not necessarily influence desired aspirations. Even those respondents who were no longer working dreamt of better jobs than they had had to date particularly the two with CF who were awaiting heart and double lung transplants. One woman with arthritis mourned the loss of status associated with employment and criticised those she perceived as work-shy and cheaters of the benefit system.

*'I miss the status if you like of being able to say yes I am disabled but I do actually work. Not all disabled people are on the dole or scrounge off the DSS if you like. It is not my fault if I cannot work and I object to the benefit system giving the same amount to people who are sitting on their butts all day who will not even try and look for a job who pretend or maybe they are depressed but I am sorry I have a hell of a lot to be depressed about but I would still be out there working if I could.'* Xanthe (JIA)



*'A career, I would want a career...I could start up my own business...Something will come in time, I have always had a belief that I'll be a millionaire somehow through my creativeness because I have some imagination. I will come up with something' Gary (CF)*

The notion then of a career in terms of a step-wise progression of jobs in pursuit of better prospects, opportunities and remuneration held true for many of these respondents. Those in manual or trade occupations aspired to management positions, others contemplated starting up their own businesses, a few were just at the start of their career trajectory.

*'I'll most definitely stay in the building trade anyway, I'm in it now so I might as well make use of it and it's good, every job I go to it's different from the last so it's interesting but I think I will go for like a college course, and get a managerial type or even just drawings and setting out, estimating I mean there's load of site management project things you can do and I'll go down that line' Will (JLA)*

Some who were out of work, however, could find it difficult to settle to a routine or commit to some meaningful activity at home. Whilst they did not feel able to sustain a job because of their health, they nevertheless thought it important to create a structure in their day to day lives.

*'I actually think that college was the best thing for me because I would get up in the mornings, no sleeping in, you get up, you getting to cough all the phlegm up and you are out and about, and you know you're away out, it's the best thing for you getting into a wee routine. See since I've left college, I am sleeping into the afternoon, waking up with all these secretions lying on my chest, waking up coughing and spluttering and just sitting about all day, and it's the worse thing for you, that's always why you get them moaning at you, the doctors and that, do something with your life, don't just sit about because then you start getting depressed and get really bored.' Eddie (CF)*

*'To start with I did not know what to do and I used to sit and watch tele which is so boring. I have just got used to it. I used to get up at the normal time but if you get up at 8.30 you think what am I going to do all day so I get up at 10.30 but people might think that is laziness but there is nothing to do and it is resting as well.' Vicky (CF)*

Employment fulfilled several valuable functions for many respondents. It provided a sense of structure, offered financial rewards, enabled social interaction, and presented individuals with an alternative identity to that of illness or disability. For those without

work, the lack of a daily or weekly plan could be hard to adjust to and generated the problem of having only one's state of health to think about. As a consequence, respondents who were too sick to work tended to develop their own routines and schedules within their day-to-day lives.

Career aspirations among the sample were unaffected by gender or disease type. Most respondents sought jobs that were well paid, provided opportunities for advancement and were fulfilling. As such, they did not differ from those of the lay public. Some UK employment policy (PMSU, 2005) refers to the low expectations among people with disabilities and longstanding illness with regard to employment options but this claim was not substantiated by the accounts of these individuals. A job, however, was not always perceived as an aspiration in itself and could be seen as just one of many priorities particularly for those in low paid work.

## **6.9 Work Adjustments**

The language of employment policy and work disability research refers to the actions undertaken by employers to support disabled people in workplace environments as adjustments. In this study, however, no individual referred to a single strategy that had been implemented by an employer to help make working lives easier. About half of respondents, though, reported that they themselves had had to carry out some kind of adjustment to accommodate the effects of their illness in the workplace. The vast majority of these were minor, practical measures that had been adopted by individuals as a form of self-management strategy. Respondents with arthritis, for example, sometimes used support bandages or special foot insoles to relieve painful joints. Some of those with cystic fibrosis avoided being placed in situations where excessive exertion such as heavy lifting was involved. In the diabetic group, many talked of their need to co-ordinate insulin administration with mealtimes. Gender did not seem to affect reported use of workplace adjustments.

*'But since then the only thing that I have really used other than my insoles has been a knee support like a strap a sport strap and I put them on my ankles as well as I have been over my ankles as well doing sport so they have been weakened but other than that I have always been the type of guy that if I want to do something I will work round my problems rather than not do something I will try to work round them to get on with what I want to do.'* Theo (JIA)

*'I feel I get tired quicker and out of breath faster and I try to get out of heavy lifting or constantly being on the move but there's nothing that needs done urgently anyway and you can always get someone else to take the lift or the boxes'* Ruth (CF)

*'The only thing is when I am having a hypo like to day for example I did have a hypo. It wasn't really bad but I could feel it coming on and it totally slows you down, it's a weird feeling, it's like you just feel really weak and really hot and sweating and my blood sugar started going really low before I even feel so that is quite scary but I can always feeling it coming on eventually and I have my glucose tablets so I had to wait for that to work and I was speaking to someone on the phone and it's horrible because it doesn't go fast enough, it takes for about 10mins for them to actually work properly, the glucose tablets'* Cara (D)

Some adjustments, however, were undertaken outside the work environment. Several respondents spoke of having to get up extra early on workdays in order to fit in treatment or to wait for joint pain to wear off. Being very tired after work was also a common complaint. Having a job that allowed flexible working hours made it easier for one or two to manage their illness without recourse to strict self-management plans.

*'At the moment, when I am waking up in the morning and it's dark, I think oh no I have got to go to work, it's going to take me ages to get out of my bed and go and get a shower and then go to my work, I can't handle it because I 'm doing 7 to 4 shifts'* Jackie (JIA)

*'I had to get up an hour or so before work to give me time to do my physio in the morning.'* Yvonne (CF)

*'I mean I think in a way working here quite suits somebody with a health problem, a chronic problem because to some extent you can make your own hours and you can, you know if you're really really knackered you could probably finish early and then work later the next day because it isn't that 9 to 5. I think now I would probably find it very difficult to go back to 9 to 5 because I'm not used to it because I probably would find that hard when I go through periods when I am very tired. If I go and start a 9 to 5 job that might cause me some problems because I'm not always at my best at 8 o'clock in the morning, sometimes*

*especially if I don't take anything like sulphazalazine but some mornings I might not being able to leave before half 9 because it can take me three quarters of an hour to get my knee and everything moving.* ' Sarah (JIA)

Whilst accommodations might be made by respondents to meet the requirements of a job, these were not usually seen as particularly demanding or onerous. Indeed, individuals appeared determined to adapt to working environments whatever they entailed.

*'It is difficult sometimes but it is more to do with my diabetes rather than my CF. Because I am in IT sometimes I have to travel to different sites to fix things and if you have different places to go the boss says have your lunch and then go but make sure you make it to all those sites. But you can't because you do not have enough time in the day. So what I will do is I will go to a site and drop into a McDonalds on my way to another site and do things like that. But that can be a bit awkward because by that time if I have not eaten for a long time I am really hungry and my blood sugar will be really low. Which is a problem for me because my blood sugar is usually high, so it goes slow, as soon as I start eating I am fine...It is just my manager. I have got used to it now and I know the sites and where I can get something to eat but it can be a problem.'* Mike (CF)

Most in the sample felt that they worked to full capacity and functioned at the same level, if not higher, than others in their workplace.

*'I do it (work) really well, because I am determined to make sure that I don't give in. I think it is also because there was somebody who used to have arthritis in the department as well and she used to have a lot of problems with her hands and she would say she could not do this and she was told to do something else. And when she said that there were people actually slagging her off behind her back, oh my hands are so sore I can't do this can't do that, I thought well I am not going to fall into that trap and sometimes it frustrates the others because I just stand and work.'* Jackie (JIA)

*'Jobs are basically what you make of them. I could have stayed in my last job and become a standard civil servant type person that does not get promoted just stays in the job, works 9 to 5 but that's not my style, I got bored with the job I was doing and looked for some change. I couldn't find it within the organisation I worked in so I looked externally. Some people did perceive it was quite a big risk moving to a private company but life is for taking risks occasionally.'* Quinn (CF)

Disclosure of illness also did not appear to guarantee concessions by employers. There was little evidence of support in general being offered to staff with impairments in work environments. Workplace disability procedures and or occupational health services were occasionally mentioned but, from respondent accounts, policies appeared not to be integrated into everyday practice. The onus seemed to be primarily on the individual to manage the demands of their job regardless of the effects of and to their chronic illness. Whilst there was a general perception that employers should be providing more formal support structures in the workplace, most were determined to put up with the working conditions they encountered for the sake of keeping their jobs. In spite of this, individuals often discounted the adjustments they had made at work or were able to cope with them in a similar way to those undertaken in other aspects of life. As such, they usually took such modifications in their stride or at least, at interview, downplayed the effects that these had made on them.

#### **6.10 Sickness absence from work**

One issue that was commonly mentioned throughout conversations was sickness absence from work. This topic represented an interesting example of the lack of 'special treatment' given to staff with longstanding illness by employers. In the sample, six of the twenty five respondents who worked or were in full-time education reported taking two weeks or longer off sick in the previous year. In four of these instances, individuals had been questioned at length about periods of absence by their bosses and two of them had been penalised through losing pay rises and in one case by being made redundant. All these respondents had revealed their health status to line managers at some point in their employment history.

*'It is really unfair because they have changed the policy and have really cracked down on it. The attendance target is supposed to be 96% and if you do not achieve that, if you are basically calling in sick, you go to a disciplinary but I was off for 5 months in hospital and they knew that but because I had not achieved the attendance target, I did not get a pay rise, I still got a bonus at Christmas but I did not get a pay rise. And when I had my review with my manager and he said maybe this year so they will review it in September but I did*

*not go back to work until December last year so there will still be a part in the year when I was off which I think totally unfair.* ' Cara (D)

*'On the face of things she knew how to tow the company line, she was saying oh well that will be fine do not worry. But Graham my direct line boss kept having to justify my position and within a year that was it. I had gone from being in charge of all these people to being without a job, what they did was instead of the job that I was doing, they re-organised things and I did not fit into the new teams so it was easy way to cut me out, it was the bottom line because it got rid of me, it got rid of my boss's boss and because that year I had had 6 weeks sickness so to say it would not affect me, I did not have evidence to support that even though the 12 years before that I had had hardly any sickness yet that year I had 6 weeks so then to try and go to get another job after that in the same line would have been difficult...'* Ursula (CF)

Even in cases where immediate line managers were supportive, it was apparent that company policies did not generally make provision for chronically ill employees in terms of adjustments made to sickness absent records or other similar measures. What was notable, however, is that when discretion in the workplace was possible, bosses of either gender tended to be most sympathetic and generous towards males in the sample rather than females.

*'My manager says she is aware of why I am off and she is not going to penalise me for it. She said I can pay you for this afternoon but I can't pay you for anymore after that. I said well I will come back tomorrow then because I can't afford not to come in. So she said she would go and speak to the manager and find out more I said well I will go home and you phone me, she said OK. She never phoned me so I came in the next day and I was actually much better so it was OK. I said to her could I take that half day as a holiday instead of putting it though as a sick day because I don't want another one. She said that was OK they normally don't let you do that'* Iain (JIA)

*'Previous bosses have just, if I have been off for just a couple of days with a cough and feeling crap they just say do not fill in any sheets because I have been off genuinely. They do not mind because they know that when I am well I am always here and I try my best.'* Mike (CF)

*'What happens is if I have a joint that flares up they will inject it that day or they will arrange an appointment for me to come back in and get injected. Well my right wrist was playing up quite badly so I thought I am going to get that injected. So I arranged for somebody to cover my shift just in case it did happen and it did, so I phoned up to tell them that it had happened and I got the assistant manager and I said I'm afraid I'll not be in today*



*as I have to have a steroid injection on my wrist. He says have you phoned personnel and put the phone down on me, which was quite nasty.'* Jackie (JIA)

Only on one occasion throughout all the interviews did a respondent (male) report an instance of good work practice with regard to sick leave from an employee's perspective.

*'They were incredibly supportive much more than I expected them to be. They extended my sick pay to as long as it was required. I was off for about a month and they paid me a full time salary even though they didn't have to. They said they knew I was ill and it was exceptional circumstances which you cannot ask more from an employer to be perfectly honest. That is the subtle difference of being genuinely ill and just taking the piss out of some organisation.'* Quinn (CF)

Sick leave absence emerged as a bone of contention among several of these respondents and in this area alone some felt that they had been unduly penalised because of health status. According to accounts, there appeared to be few proactive workplace policies operating that provided discretionary allowances for those with chronic illness. The gender difference regarding males being given more sympathetic hearings from line managers with respect to sick leave may just reflect sample bias. However, there are other explanations that could account for this finding. Concern about levels of sick leave in the UK has been growing in recent years (Barham and Begum, 2005) with employers becoming increasingly aware of the direct and indirect costs of absence to their organisations. These young adults may have experienced part of the general drive in workplaces across both public and private sectors to clamp down on the amount of absence taken by employees. National (UK) statistics reveal that female employees and younger adults aged between 16-34 are more likely to be off sick from work at any one time and employers believe that almost 20% of absence is not genuine (Barham and Begum, 2005). These data may help in part to explain the more favourable response awarded to males over females with regard to sick absence from work. Alternately, this result may reflect gender attitudes and gender inequalities within UK work environments. With regard to this study, the difficulties encountered by some of these individuals over sick leave absence are of concern particularly given their susceptibility



to frequent episodes of illness. The legal position on this matter is also somewhat vague and only likely to become clearer when judgements are made at Court hearings. The next section explores the issue of perceived discrimination at work.

### **6.11 *'I have managed to stay here long enough to prove to them that I can do it so I doubt they would do anything to me': experiences of and attitudes towards discrimination at work***

In spite of the apparent lack of supportive workplace policies for people with chronic illness, instances of felt discrimination were rare. It was unusual for respondents to regard any case of bad practice they experienced as personally discriminatory. Instances of poor behaviour doled out by line managers were perceived as poor management style rather than company policy. As such, these individuals thought that they received, or would receive, the same opportunities for advancement (promotion or similar entitlements) as others at their level. Indeed, in the minds of many respondents, discrimination was more likely to be encountered at the hands of unknown employers than actual ones.

*'I think that if people wanted to treat you differently then ultimately it shows a degree of small mindedness on their part. They are not giving you a chance and if that's the way that they wanted it to be then I would be better off not working for them.'* Colin (D)

*'I'm not very career minded and the company I work for is very good. Not just about my CF but company outings and as I said I like the people there. It's all quite important as well. To be honest there is nowhere in the company that I can go because most people are in the transportation side but I am not at all ambitious. I am quite happy in my little role being told what to do.'* Yvonne (CF)

Indeed, most felt that the high standard of work they provided protected them from discriminatory action.

*'I have managed to stay here long enough to prove to them that I can do it so that I doubt they would do anything to me. They would have to be really hard nosed, I don't think so. I*

*have built up a network of friends and colleagues. Those that have left have asked me would you come with me, would you work with me if I get this job. If I ever needed to move I don't think it'd be a problem.'* Mike (CF)

A couple at the start of their careers thought that discrimination, if it occurred at all, would likely be an out of sight phenomenon or would not be practised if disclosure of health status had occurred.

*'I know that if they sacked me because I had arthritis I'd make sure I took them to court because they can't do that. They can't discriminate against somebody. As long as you say to somebody this is what I have got and keep them up to date tell them what medication you are on, you should be alright.'* Jackie (JLA)

*'To be honest I wouldn't say I've got the knowledge of working for long enough to say there is or there isn't (discriminatory practice), I mean I couldn't really say I've seen it myself because if it is happening to me, it's obviously going to be out of sight, I'm not going to be able to tell. I mean in this one I got the job as well and they came to ask me when I told them what diabetes I had so I mean I was telling my boss and he say oh right I mean because I'm well controlled and everything...'* Peter (D)

While the perception of potential discrimination at work was universally accepted by these groups of individuals, it was interesting and somewhat surprising to find that only in isolated cases did people feel that they had been personally discriminated against in the workplace or at the point of application. Pinder (1995) in her research came across similar instances of refusal to concede to such a charge. This finding would benefit from further investigation.

The UK Discrimination Act may help to provide some clarity with regard to the types of workplace adjustments that employers might reasonably be expected to adopt to support individuals with chronic illness. In the case of sickness absence levels, advice on this area could perhaps be provided, however, legislation might be rather a blunt tool for managing the nuances of employer-employee relationships. The mainstreaming of employment policies that govern attitudes and behaviours in the

workplace throughout Britain may be one way to tackle this issue. Guidance could be given or a minimum standard set for the implementation of inclusive working practices for those with ill health or impairment. In so doing, considerations of justice and equity would have to be balanced against organisational efficiency and productivity when the trade-offs between these two may not be easily reconciled.

Finally, in talking to respondents about aspirations, illness and employment, the topic of ambitions and projected hopes was raised. This last section of results concentrates on the current concerns of these individuals with regard to their health and prospects for the future.

## **6.12 Future Concerns**

Half of the respondents did not express much concern over what the future might hold. Males in the sample were more likely to take a phlegmatic attitude to potential difficulties and did not think it was worth their while to worry about something that might never happen.

*'I do not think about the future that often. I take each day as it comes as things can happen, I could walk out of the door and be hit by a bus or something.'* Oliver (D)

*'I just live everyday as it comes, just day for day...I do not look to the future. The only time I will look into the future is when I go on holiday....Somebody once said, what do you think about dying, why are you asking a question like that when you ken I have CF and that. I could cross the road and get knocked down by a bus or I could have a brain haemorrhage, anything could happen. It does not affect me, I dinnae think'* Fred (CF)

*'Certainly as I get older I'm likely to get worse, I have thought about it but I'm not too worried about it, I mean I suppose I'd be quite a lot older and maybe sort of in my retirement, I might have bad arthritis but it's not worth thinking about it (laugh) If I'm going to, I'm going to so (shrug)'* Xavier (JIA)

Severity of illness did not appear to be linked to more expressed anxiety. Those who were less impaired by their diagnosis were just as likely as others to have misgivings about future events. There was, however, an age-related effect whereby younger respondents (of both sexes) were seemingly less bothered than older ones about the effects of their condition at some later stage.

*'I'm confident in my life at the moment and the way I work and don't worry about further down the years kind of thing like well I do sort of think well with the smoking, perhaps I will give up smoking by the time I'm 30 because I've been smoking since I was 16 and I will give up but at the moment people are always on about it and at the end of the day, that's what I choose to do and that's my vice at the moment and if it's going to affect me later on in life well I'll have to deal with that when it comes'* Peter aged 23 years (D)

*'I suppose it depends on how well I can keep my blood sugar levels under control as to whether I get complications. And I try to keep tabs on things... but I suppose I've had it for over 14 years now and I have to think about it, it does concern me sometimes'* Diane aged 27 years (D)

*'I'm 21, I don't really think in-depth about it (the future) because I think if you did you would wrap yourself up in cotton wool so I just live day by day and don't have any worries or concerns about anything, I think that's an easier way'* Ruth aged 21 years (CF)

*'I can see that my lung functions are not getting spectacularly better and yes I do think well could that be the future. It changes everything because you think am I going to reach 40 let alone pass that.'* Ursula aged 28 years (CF)

When concerns were spoken of, some men in the sample talked about these somewhat glibly or obliquely, tending not to attribute fears directly to themselves. In so doing, these respondents were able to create a certain distance between themselves and any unpalatable speculations they might have. Females rarely used such dissembling techniques in their discussions of difficulties they may encounter.

*'They (doctors) are either telling me a lot of crap or they are quite happy and I have no need to worry about the future. If I have to get my legs chopped off when I am 50, well it's gonnae be a bother but it's gonnae happen.'* Christopher (D)

*'Occasionally I hear stories of people who have had leg amputations and toes taken off and that kind of thing which worries me a bit or people losing their sight completely, I do not fancy that. If I lost a leg well that would scupper my organ playing as I would not be able to use the pedals in any way, if I lost a finger then I might as well just kill myself because it just wouldn't be worth it. And then if I lost my hearing well it would be just the same. Obviously I should take these stories seriously because they do happen, but I am pretty blasé about it all and say they could not happen to me.'* Hugh (D)

Anxieties raised at interview included the likely effects of illness on the body, possible future impairments, side effects from medications and/or complications of the disease process. Very few mentioned the loss of job prospects as a potential cause for concern. Some of those with cystic fibrosis (number = six) and two respondents with arthritis specifically alluded to the possibility of reduced life expectancy. Men were typically more impassive than women when describing the prospect of such an event and some continued with the same light, jokey manner described earlier.

*'I'm not scared of dying, it's more waiting for it (the transplant), that's why we are on the transplant list.. As long as I get what I want at my funeral but I am probably not going to know about it anyway. The things at my funeral are not really for me, it's for those that knew me. Because if it goes as I want they will know it was me. They will know that it was my thinking. You have got to die, you can die before the transplant or you die after it.'* Gary (CF)

*'Always at Cambletown (children's hospital) they would say if you do the things you are supposed to do you will live to a grand old age...and then when you went to General Hospital (adult service) they made it into reality and they said you know you might not live until you are 25 if you get really ill and you do not manage to get through a transplant and that kind of hit home. And it is not advised for you to have children just in case you can't stay well for the 9 months, which kind of shocked me and worried me because I have always wanted to be an ordinary mum just the sort of life that everybody has and then it just got wiped out. So it does worry me a little bit that I will not be around to enjoy everything so that is why I try to enjoy and try to do it now so that I have done it.'* Vicky (CF)

*'I am 21 on the 22nd of this month, so I will get my party (laugh).'* Eddie (CF)

About three quarters of the women in the sample (number = 10) but none of the men spontaneously broached the notion of pregnancy and having children in relation to future concerns. All were childless at the time of interview except for one respondent

(Colin) with diabetes who had since separated from his wife and was living alone. In CF, males tend to be infertile or at least sub-fertile and women may also experience problems with fertility. Doctors invariably warn against pregnancy for those with CF due to the strain on the heart and reduced lung function whilst pregnant and the effort of looking after children thereafter. Complications can also occur during pregnancy for those with diabetes and arthritis. Women, who were taking methotrexate, a disease modifying drug for arthritic conditions, were advised of its toxic effect on foetus formation and cautioned against pregnancy.

At interview, women talked about the prospect of having children or remaining childless with mixed emotions. For some, it was a matter of wanting something they felt was forbidden, others anticipated a time when they might be healthy enough to contemplate starting a family, a few felt that the physical effects of pregnancy could further damage their health. One or two recognised that they were simply not well enough to look after children in the long-term.

*'I can't have children and all my friends are having kids and stuff like that, I am not particularly into children but I resent the fact that the decision has basically been made for me. My husband is not bothered about kids at all so that's OK. Lots of people can't have kids so that is just tough' Yvonne (CF)*

*'I know that in the future I would love to have kids and stuff eventually and I have to admit that my sugar and that goes up during working and at different times of the day although overall my control is OK if you want and try and have kids you have to try and keep everything right' Beth (D)*

*'Occasionally I worry about, I don't have any particular plans to have kids but if I became pregnant, what would I do then, I'm sure it would be all right actually because I think my kidneys probably would be able to cope better than you think but would I be able to cope you know, would I be more exhausted, would I have other problems, would other medical problems kind of crop up?' Sarah (JIA)*

*'Even although I have never been somebody who had been strong for having children it is like as soon as you are told you cannot do something you want to do it. It was another thing off the list that you can't do' Ursula (CF)*

Particularly among women with arthritis, concerns focused on the one hand about the effects of medication on pregnancy and on the other about whether they would be able to cope physically with looking after children full-time.

*'No matter how ill I am, I love kids to bits and it is one of the things I do resent about my illness is a, due to all the medication I have had I am probably not able to have any and b, that my health is such now that they say that your disease goes through a major remission during pregnancy but it comes back with a vengeance, it could be worse than it had ever been. I can't be that selfish.' Xanthe (JIA)*

*'The only thing that does worry me when I sit and think about the future is being able to have a family one day, I do not know if I could cope with the children after. I think maybe I am not very maternal at this moment in time but I do sometimes sit and think because I am not allowed to get pregnant on my tablets and I know that I could not cope off my tablets, but it is a while away before any thing like that is going to happen, but that is the only thing that worries me a bit being on the medication how my bones would cope if I was carrying a baby about and things' Bryony (JIA)*

*'I have a theory that I would not be able to have kids because I have been on medication for so long and because I have arthritis. I don't know why I just have this thing about it. I don't want kids at this age anyway so I will wait until I get to that hurdle. It's just a fear I've got' Jackie (JIA)*

A number of concerns were expressed about the future but these were predominantly from females and generally did not include worries over employment matters. Men appeared much less apprehensive and often discounted any potential problems that might occur. Severity of disorder was not obviously linked to more expressed anxiety and younger adults were markedly more blasé than their older counterparts. Women in the sample often spoke of the tension between lives as desired and lives as experienced in relation to the prospect of having children.



### 6.13 Conclusion

Respondents in this study had experienced different types of employment trajectories depending on factors such as age, educational attainment, health status and types of entry into the workplace. In general, formal organisational support for employment (for example, advice from employment services, careers guidance etc) had not been available nor apparently sought by these individuals. Some jobs had been obtained through informal networks which obviated the need for disclosure about health status. Revealing one's condition to potential employers was widely perceived to diminish one's chances of securing work so most provided information on a needs-to-know basis. Part-time working was not widespread amongst the sample and notably only applied to females in the study. Jobs were predominantly valued if they were well paid, provided opportunities for advancement and were fulfilling. Work, however, was not necessarily regarded as an aspiration in itself. Five of the sample were not in any form of work, training or education at the point of interview. Several respondents reported making adjustments to working lives but these were usually not recognised by employers themselves. Whilst the perceived potential for discrimination at work was high, most felt that this would most likely occur to *other* people rather than themselves. As such, bad practice in the workplace was largely perceived as poor management style rather than organisational policy. Severity of illness did not appear to be linked to more expressions of anxiety about the future. Female respondents talked with mixed emotions about the prospect of having children or being denied children because of health status but few concerns were made of potential employment problems in the long-term.

Participant accounts of their negotiation of employment underlined the interdependence of agency and structural processes such as education and social background. The ability of individuals to secure and maintain a working life (i.e. to exert agency) was made easier through opportunities afforded to them through family

aspirations and entry into higher education. Employment as an outcome was therefore inextricably linked to early experience and favourable social circumstances. Whilst relative health in spite of chronic illness was clearly a determinant of working status in the sample, personal situations also affected individual motivation and desire to work. The types of employment available to participants influenced the choice of whether to seek work or to claim disability benefit. Access to higher educational or work-related networks extended the social contacts of individuals and afforded them greater opportunity to advance their careers.

The next chapter places these findings in a wider theoretical context of other research and literature in the areas of young adults, chronic illness and work.

## **CHAPTER 7: THEORETICAL DEVELOPMENT OF RESEARCH FINDINGS**

### **7.1 Introduction**

A diverse range of disciplines have amassed a wealth of research about chronic illness from different perspectives and theoretical backgrounds. This has led to parallel programmes of work being undertaken largely without reference to each other which when reviewed together has exposed disconnections and gaps in the knowledge-base. There is, for example, very little empirical research about career aspirations and the experiences of paid work amongst young adults with long-term health problems despite the importance of chronic illness for medical sociologists, psychologists and occupational health practitioners over the past thirty years. More recently, disabled scholars have begun to examine the social and economic consequences of disability employment policy for disabled people and some of this work has relevance for those with chronic conditions. The holistic approach adopted by researchers in the study of young people and social exclusion would also appear to offer theoretical opportunities to increase an understanding of how those with child-onset disease fare in the labour market as adults. This chapter explores some of the findings of the research in more depth and places them in context of a more theoretically-developed framework in order to understand some of the differences in outcome for respondents in the study.

### **7.2 The presentation of respondents at interview**

Respondents presented themselves at interview as morally competent young people in their management of illness. Most were interviewed in their home environments although one chose to be seen in a workplace, another in a tea-room and one in a hospital environment. The location of interview as well as the interaction between myself as the researcher and those who took part affected the ease of communication, the lengths of discussions and the ability of individuals to be fully open about their

experiences, actions and attitudes. Notwithstanding these differences, the interviews produced rich and varied accounts of school lives, encounters with health care services and pathways into higher education and/or employment.

In examining the dialogue and the ways in which individuals talked about their experiences, respondents appeared to use a variety of strategies to demonstrate that they were competent to manage their illness. They emphasised their knowledge and understanding of their chronic condition and mentioned how attuned they were to bodily changes and alterations in health status on a day-to-day basis. Other examples included respondents' accounts of their decisions to change or stop medications which were perceived to be detrimental to them in the long-term. Many also discussed how they tried to maintain and improve their health by going to the gym, keeping an eye on their weight and following health care guidance so long as the advice received was deemed to be useful and appropriate to their circumstances.

These descriptions of agency in the control of illness are contrary to Bury's conceptualisation of chronic disease as a profoundly debilitating experience. Bury (1982) put forward his argument that adult-onset illness represents a major disruptive event that challenges the structures of everyday life. His theory is framed around three aspects of disruption; the breaching of taken-for-granted assumptions, the need to rethink one's biography and the requirement to rearrange personal and social networks as a consequence of illness. In this study, all participants had been diagnosed with their condition during childhood years. Few could recall a time free from symptoms of disease or without reference to their diagnosis. Condition management had formed part of the vicissitudes of their life and was central to participants' sense of biography and sense of self. As such, most were able to construct and reconstruct their own identities and life styles to resist a 'crisis' model of illness experience.

Several respondents often compared themselves to others with the same condition whether that was a sibling, a friend or a generalised 'other'. This strategy appeared to serve different purposes for different individuals. Some females with cystic fibrosis and arthritis seemed intent on distancing themselves from those they regarded as stereotypical of their condition perhaps in order to assert their own sense of difference and individuality. For others, making comparisons provided the assurance of a shared experience of chronic illness in as much as one's health state could be considered as part of a wider phenomenon.

The emphasis placed by respondents on personal self-care also appeared to reinforce this view of individuals as knowledgeable, rational and competent people in their management of conditions. They rarely referred to others when they discussed how they dealt with their illness and reportedly relied on their own sense of judgement with which to make decisions about daily treatment and future care. Such displays of self-sufficiency seemed to suggest that respondents felt personally responsible for the maintenance of their own health. The expressed reluctance by some to discuss bothersome day-to-day concerns with family, partners or close friends would also appear to add weight to this conclusion.

Participants mediated the dichotomy between disability (socially caused restrictions) and functional impairments. There was an overwhelming recognition amongst the sample of societal attempts to label them by reference to their health status. Whilst this could be beneficial in certain cases by helping participants access work, higher education or benefits, it could also act to stigmatise and limit their potential. Most individuals in the study denied any sense of difference due to their diagnosis alone. Disease status was not perceived as an essential defining characteristic and many resented any attempts by health professionals or others to mark them out as different.

The respondents in this study, although young, were long-term users of health services. They had come into contact with many different types of health practitioners over a number of years and had regularly attended hospital outpatient clinics. At interview, only about a third of the sample appeared to be satisfied with the care they had received with a few nurses being singled out for special commendation. The other respondents made numerous critical comments about their health care although none of them, to my knowledge, had ever made a formal complaint to a NHS organisation. Negative experiences of care can have long-term consequences on health-related behaviour and may undermine subsequent health care encounters (Coyle, 1999a). Service user views therefore need to be taken seriously if the move towards a more person-centred model of care is to be achieved with health professionals being prepared to address the problems underlying lay-practitioner relationships.

In a paper exploring dissatisfaction among service users in London, Coyle identified how threats to personal integrity underpinned almost all negative experiences of health care (Coyle, 1999b). These included feelings of being dehumanised, objectified, stereotyped, disempowered and devalued. Research suggests that dissatisfied individuals often attribute cause, responsibility and blame for their untoward experiences of health care onto health practitioners (Coyle, 1999b; Mulcahy and Lloyd-Bostock, 1994; Nettleton and Harding, 1994). In this study, criticisms were levelled at the professional integrity of health care staff with allegations made about authoritarian approaches, unsympathetic attitudes as well as the inflexibility of the NHS as a system of health care. Some respondents also disapproved of how health professionals seemed to (mis)apply their medical knowledge particularly in circumstances that relied on prognostic assumptions such as recovery rates or the likelihood of experiencing a specific side effect. For those who had multiple health problems, the lack of cross-speciality interaction was an additional source of frustration.

Health care encounters are complex constructs. Individuals need to maintain their health or confine their illness within acceptable barriers in order to carry out their social roles. The concerns expressed by these respondents' reveal what it might be like to be on the receiving end of health care services today. Their dissatisfaction offers insight into the attitudes and actions of health care professionals and, in so doing, offers various mechanisms by which future health care delivery may be improved. The experience of illness, however, and the ways in which individuals react to similar circumstances are dependent on the available resources from which they are able to draw. The next section examines the theoretical orientation of the research in more detail and explores the biographies of the respondents against the backdrop of wider social processes. In this way, comparisons can be made among and between the individuals in relation to their outcomes and the meanings that they attach to their behaviour.

### **7.3 Theoretical framework**

Chronic illness is multidimensional in character and consequence. The use of social capital and the theories underpinning social exclusion can provide a framework for understanding the data in terms of the interplay between agency and structure in the accounts of respondents in the study. Part of the attraction of social capital is the way it can act as a link between the micro and macro levels of analysis, that is between the actions of individuals and groups and the social processes and structural practices of society (Schuller et al., 2000). Social capital is a somewhat murky concept but the works of Bourdieu (Bourdieu, 1986), Coleman (Coleman, 1994) and Putnam (Putnam, 2000) appear consistently in the literature. These authors refer to the types of resources which are available to young adults (and the wider community) that affect beliefs, behaviours and outcomes.



The concept of social capital or the quality and quantity of networks available to individuals provides the conduit for other forms of capital. Cultural capital, used here to include family background and education, helps to explain why young adults can vary in their attitudes and actions. Access to financial resources through benefits, employment and/or private means, termed economic capital, is a particularly important factor for young adults in the UK where the transition to adulthood has become protracted, risky and convoluted (Jones, 2005). The relational aspects of these different forms of capital interact with and are influenced by location, structural forces and the efficacy of policy delivery. Social capital is conceived of as a source of power and currency which can be drawn upon and converted into human capital (in the forms of skills and abilities) through networks between individuals and families, between families and communities and in opening up new links through education and employment. Networks such as these can also bring about changes in attitudes and affect the choices that people make during the course of their lives.

Social capital exists in the relationships between individuals but is also defined as the ability of people to work together in groups and organisations (Fukuyama, 1995). Such groups might include extended family ties, faith alliances, peer networks and act either as helping or hindering forces to social mobility. Putnam (2000) refers to bridging and bonding social capital that binds groups together and gives them access to wider chains of affiliation. Bonding capital is akin to strong social links such as those between families and/or ethnic groups which are often located in the same neighbourhood and enable people to get by. Bridging capital, on the other hand, is seen to comprise weaker, less dense networks such as friends from different groups, school teachers and work colleagues that help people to get ahead through access to influence and opportunity. In this way, a distinction is made between those who live in socially deprived communities who often have strong, supportive ties but fewer prospects for

social leverage and those in more affluent groups whose networks include greater possibility for advancement.

#### **7.4 Social identity**

The data from this study point to the dynamic interplay between the individual, the opportunities or resources available to them, and the structuring effects of health status, locality, class and gender. Factors affecting the respondents' beliefs and the choices they made were rooted in their social contexts. Their accounts of actions and experiences provided some access into how key decisions were made about health care, about education and about whether or not employment was sought which shaped the outcome of their personal circumstances at the point of interview. Respondent biographies can be viewed against a backdrop of wider social processes as well as in regard to other transitions taking place in their lives.

Individuals form dispositions on the basis of their constructed identities, their personal situations and the influence of locale and family background. The vast majority of these young adults were born and brought up in central Scotland although one was English, another was Irish in origin and a third was Australian. This latter respondent was working as an agency nurse in Lothian as part of a round-the-world trip and had gained access to the NHS through a health insurance scheme. All respondents had developed a chronic physical illness at some stage during childhood but the effect of long-standing disease for those in the sample was variable in terms of present (and likely future) outcomes.

In the UK, the transition to adulthood has become more complex and fragmented over the last thirty years (Jones, 2005; and see p. 51-52). The basic patterns to adult independence have changed with a longer period of dependent youth and young people being encouraged to delay entry into full-time work by accessing higher

education or training (Furlong and Cartmel, 1997; Jones, 2002; Jones, 2005; Jones and Wallace, 1992). Age has therefore become an unreliable marker of adult identity. In this study just over half of the sample (n = 16) were living in their parental home (age-range between 20-28 years), eleven with both parents and five with a lone parent (see p. 130-131). Respondents were not explicitly asked about their family make-up or social background although through discussion it was apparent that within the sample there was a mix of biological, step, absent and lone parental networks in operation.

In a longitudinal study, Thomson and colleagues found that the identities that young adults assume are multifaceted and are not necessarily centred on academic or work labels (Thomson et al., 2004). As they progress, young people develop different identities in different areas of life reflecting different degrees of competence in each. In this study, respondents expressed how they were able to carry out a range of roles within the spheres of their social worlds; education, work, leisure and family. Few were happy to take on an illness identity unless it afforded them some perceived benefit, such as access to training and employment or part-time work. There was sometimes a contradiction between these identities so that it was possible to be simultaneously an individual with a chronic condition, a badly behaving member of a family, a good or poor partner and a respected work colleague all at the same time. Two quotations have been selected from the interviews to typify these kinds of ambiguities.

*'I used not to get on with my Mum and Dad but that was through the way I behaved, but obviously when you are out of the house it's different as you don't see them everyday. It's brilliant now because I'm older and ken a bit more grown up... I've got my girlfriend, I've been going out with her for 7 years now and when I was smoking and drinking it's my health which was going downhill and I was just dragging her down hill with me so I stopped all that...' Fred (CF)*

*Kate (JIA): I get frustrated I just shout, I just, you know sometimes have a go at them because sometimes, they're doing something, I don't know.*

HA: Are you talking about your family here?

Kate (JIA): Yes and my boyfriend. He gets, I said to him, I don't know how you stick with me because sometimes I can be really good but at other times I get really frustrated and I just need, you know, not be and get out...I like where I work because we work as a team and we don't it's not all bitch, bitch, bitch, you know it's, everybody just gets on'

Respondents also frequently spoke of changes in identity over time in response to different levels of responsibility and autonomy. As they entered higher education or started work so their friendship groups widened and offered different cultural affiliations and lifestyles. Those who had less access to independent pathways had more constrained choice or opportunities in making new social contacts. The contrast between the networks available to different individuals within the sample was sometimes very telling. Eddie, for example, was not in any training, education or work at the point of interview and had moved back to live with his mum having recently split up with his girlfriend. Iain, on the other hand, was working full-time and had had to reduce his social life in order to spend more time with a new partner.

*'I had my own house with my girlfriend, we were living there we were engaged and living there for over a year, but then we were just arguing and then you know, too many problems...Actually since then I've got a bit depressed, sitting on my own...and it's good that my Mum made me move back here, I'm just like sitting about, I do absolutely nothing whatsoever. It's just getting really boring and depressing actually and I think back to when I was at college with my house and my girlfriend, and there was something to my life then, you know.'* Eddie (CF)

*'I don't go out as much as I used to, when I first went there (workplace) for a year or so I was pretty mad for it and going out a lot and all the office stuff but not so much in the last wee while but that is mostly to do with settling in with my girlfriend.'* Iain (JIA)

New opportunities and constraints emerged over time structured by local conditions as well as through factors such as health status (deteriorating or improving) and changing circumstances. Xanthe and Vicky had both given up work because of poor health and this factor had reduced the number of social contacts they encountered. Others, such as Anna, Xavier and Hugh were on the brink of enlarging their cultural and social

networks as they finished higher education and approached the realm of paid work. For the latter respondents, health status was not perceived as a hindering factor in their ability to gain employment and forge a career.

*'We are getting very anti-social as a family, we like our wee unit and we are happy in our wee unit and we do not need. I used to need loads of outsiders...a couple of years ago I would say I'm feeling good today and I want to go out and I would be sitting with a face like a wet weekend because there was nobody that was free...now I have a list of people that I should be phoning and I don't have the energy.'* Xanthe (JIA)

*'I want to do assistant stage manager type work or wardrobe work they're the areas that I love the most. You could be working during the day but then going on and doing a show at night so it just depends on the workload and what is happening and everything... I'm sure if the catering is there well but em as long as I am aware of it (diabetes) myself then I can sort it and make sure I'm OK. I don't think it should affect anything'.* Anna (D)

Those with deteriorating health or who were not in paid work had fewer personal and social networks in the sample. Whilst this had the potential to be isolating (see Eddie's comment on previous page), others such as Xanthe, Vicky and Fred were able to maintain and take advantage of close friends and family relationships. The impact of unemployment constrained the opportunity to make new social contacts and be involved in wider community networks.

## **7.5 Social background and education**

The respondent accounts of school experience provided a glimpse into the cultural capital of their home lives and the level of structural effects (limitations and opportunities) apparent in their pathways to adulthood. Most respondents had received a state education (number = 26) with over a third (number = 12) leaving school at age 16, the vast majority having obtained standard grade educational qualifications. Within this subset of young people with ostensibly similar backgrounds, important differences could be detected with respect to family background, cultural aspirations and attitudes to employment. Some young people had lived with a lone parent or in households where there were stretched financial resources at some point during

childhood years. Notwithstanding this factor, there also seemed to be disparities between respondents in terms of the types of support available to them and in respect to parents' and teachers' engagement in their educational welfare and an expectation or otherwise towards working lives.

According to Coleman (1994), Bourdieu (1986) and others (Bell, 2001) the family is perhaps the most important resource for young people and acts as a transmitter of social and economic capital through parenting practices, practical support, social networks and expectations. Families act as mediators of structural factors and can facilitate or impede social mobility. Higher socio-economic status and intact family units have been found, perhaps unsurprisingly, to have a positive effect on the educational attainment of young people (Catan, 2004; Ho Sui-Chu and Willms, 1996). Parental involvement in children's lives can also have a long-lasting impact on well-being and behaviour (Sacker et al., 2002). The connection between families and later adult outcomes is especially important for children experiencing economic hardship (Hango, 2007). A stable family environment with parental commitment appears to override some of the effects of poverty and disadvantage (Hango, 2007; Schoon and Parsons, 2003). In one study, the interest shown by parents in the education of those aged 16 was more important in predicting whether or not children stayed on at school than attention given in earlier years of childhood (Hango, 2007). Investment in both bonding and bridging social and cultural capital during early years therefore appears to be significant in affecting positive transitions to adulthood.

In this study, there seemed to be various differences among the sample in terms of social background and educational attainment according to accounts given by respondents. Even among those with similar academic qualifications at the point of interview, the motivation to work and expectations for careers in the longer-term varied seemingly as much by the cultural capital of their home lives as through their

state of health. Mike and Gary, for example, both had cystic fibrosis and had left school at 16. Whilst neither had much sense of the type of work they wished to pursue at that age, their response to seeking employment seemed to produce different outcomes from the outset.

*Gary (CF): I can't really remember what I did (after leaving school), just enjoyed life a wee bit, I think. But I was not looking after myself, I was doing things that I shouldn't have been doing (alluding to a phase of illicit drug taking). I wouldnae have lasted in a job anyway.*

*HA: why not?*

*Gary (CF): Because it wouldnae have worked. I didnae have the attitude, I had a bad attitude at that time.*

*'I did nothing for 6 months (after I left school). I applied for a few jobs here and there. One of my mates from school, I was in a few of his classes got really friendly with him and we both got a job at Crossways (supermarket), So I was in the bakery department and he was in checkout and that was a really good laugh because everybody who was there had just either just left school or they were at university so we just got a bit of pocket money and went out, had nights out...and then I realised after a few months I really should get a proper job so I applied to the council at the time on a training course.'* Mike (CF)

Respondents often made allusions to the influence of family members on how they managed their illness and how they viewed educational attainment whilst at school. Some parents appeared to have made active steps to encourage and support their children to succeed academically whereas other families seemed to place less importance on educational achievement.

*Ursula (CF): We were always going to university, there was no leaving school, everybody had to go but I think*

*HA: Was this your parents' expectations for you?*

*Ursula (CF): Yes, my dad, at that time we were all doing O and A levels, degrees and then you could do whatever you wanted to do after that. I just did not think about leaving school, it was always O, A and then degree and whatever.*



*'I went to St. Martin's, it's a Catholic school. I am not a Catholic but my mum sent me there because she liked Catholic schools' teaching apparently, she thought they were better.'*  
Iain (JIA)

*'My mum, I don't get on with, I live with my dad and he likes a bit of a drink and he mollycoddles you a bit too much...school was alright I saw my mates but that was about it. I didn't like the teachers, some of them weren't very understanding...and a whole group of us used to mess about in class...'* Christopher (D)

In the last two examples, Iain and Christopher were each brought up by single parents and whilst the former was firmly committed to securing a worthwhile job with promotional prospects after leaving school, Christopher eventually drifted into his job as a warehouseman. The different emphases placed on education and work by different family cultures have their origins in wider social divisions. Parents' beliefs affect how and the extent to which they provide support for their children and, in so doing, they shape the attitudes with which young people view their own futures.

Currently and increasingly young adults need to depend on parents or carers for financial support and resources (Jones, 2005). The extension of economic dependence in youth has increased the power of parents to influence young people's choices. Yet, there are strong and persisting traditions in working class communities that adult status is achieved through employment and progression through work experience rather than in obtaining academic qualifications (McDowell, 2001; Stafford et al., 1999). In a literature review, Jones (2005) reported on a culture of white working class masculinity prevalent in British society that is bound up with an anti-school ethos and which valorises manual work even though few opportunities exist for long-term and rewarding employment in this field. McDowell (2001) found that among the white, working class men she interviewed, they expected to become breadwinners and had definite ideas about the kinds of jobs appropriate for men. In this study, Gary seemed to express similar views in his argument for increased incapacity benefit to make up for his inability to sustain work through ill-health. He described his wish for a main wage

earner income commensurate with a working salary that would include cover for any dependents in the household.

*'I think they should give us just a wee bit more money to maybe help us through it, make us feel a bit more like we can provide. What if you get a relationship and you get a wife and that but you cannae work, and what if you meet someone who has a bairn. Not that I have but most people that have would feel a bit inadequate, because they cannae care for the household and the woman is wearing the trousers because she is bringing in the stuff, she brings in the bread. I think the man should be able to stand on his own two feet as well as the woman stand on her two feet. But the man is the man. It's his pride, his palace. He looks after the woman and the bairn or just the woman. Women do not like to look after the guys, women like guys to look after themselves.'* Gary (CF)

Education potentially is a levelling influence on inequality and disadvantage wrought through social class division. Academic achievement is not only associated with parental expectation but also that of teachers and others (Coleman, 1994). Children generate their own social capital links (positive and adverse) through friendship networks, peer groups and school and out of school activities. Low expectations amongst teachers, parents and individuals themselves because of social class, health status and other factors are also likely to influence labour market outcomes. Whilst the educational system can help to address inequalities through disadvantage in cultural capital, at its worse it might also simply reinforce them (Jones, 2005).

Whilst this study can only point to possible differences in the social backgrounds of respondents, their accounts provide some indication of the types of influences that impacted on their lives as they matured to adulthood. Teachers were frequently criticised by those in the sample for failing to address educational weaknesses or to provide appropriate moral authority in dealing with themselves as children with long-term illness. Only one in the sample described any active intervention taken by a school to try to make up for deficits in education caused by school absence. Educational institutions offer opportunities to assist in the full development of human capital of young people in the form of skills and academic attainment, particularly

those who are disadvantaged through social class and/or health status. The engagement of teachers in the welfare of pupils could play a part in improving adult outcomes for those with chronic illness in relation to school performance. They could also assist in ensuring young people acquire the 'soft skills' important to potential employers such as written and spoken communication, enthusiasm, competence in team-working and dependability.

## **7.6 Respondent outcome at the point of interview**

In this study, the impact of ill-health seemed to intensify the effects of socio-economic and financial disadvantage (and low social, human and cultural capital). For those with few or no qualifications and poor personal links, it was not only difficult for them to secure work from the outset (both Gary and Eddie, for example, had never held down a job for longer than three months at the point of interview), there were also less opportunities for them to remain in employment once their health had begun to deteriorate (the experiences of Vicky, Xanthe and Fred also appear to add weight to this claim). The ability to obtain and maintain a job was made easier for those with higher levels of educational attainment and access to supportive family networks. In addition, these individuals were usually able to be employed in relatively sedentary-type work which could be managed without too many adverse effects on their health. The structural barriers to employment which this study seem to point to were unfavourable family circumstances with no parental expectations to work, lack of attainment of any educational or employable qualifications in the face of significant chronic illness or deteriorating health.

Perceived severity of illness was not examined in this study but others have found that perceptions can differ between individuals from that of their carers/family and health workers (Abbott et al., 1995; O'Neill and Morrow, 2001). This may also explain some of the differences between respondents in terms of their own expectations to work and

those of others, including employers. In other words, the determination to have a career backed up by educational attainment or employable skills, family support and high self-esteem may override much of the impact of chronic ill-health. Quinn and Ursula, for example, had university degrees and severe cystic fibrosis yet they had both been able to hold down successful careers in spite of periods of hospitalisation. Longitudinal studies may help to explore the differential impact of illnesses on employment as individuals continue into adulthood and may highlight whether there is a point at which disease severity becomes insupportable with working careers. This point, however, may differ according to circumstance so that individuals with similar clinical parameters may have different working trajectories depending on the types of work they undertake, their personal sense of motivation and the resources that are, or perceived to be, available to them.

The aspirations and expectations of respondents in the study were also affected by local labour market conditions as well as by health status. Those who had high bridging capital, that is access to people with influence such as employers, were able to bypass the usual employment channels and enter work through personal links. Four respondents in the sample had secured a job via this route. Others who were less fortunate (such as Jackie and perhaps Lara) were employed in occupations for which they were probably over-qualified. It is possible that their diagnosis of chronic illness had contributed to this situation.

*'It (job as a shop assistant) started off as a part-time job while I was at university and it's now a full-time job as I've applied for loads and loads of jobs but I've just not been given one in my field' Jackie (JIA)*

*'(My job) is not high profile, I'm not up there in the big ranks, I'm just in the lowly bottom...but if the opportunity arises I will go for promotion' Lara (CF)*

Labour market options open to these young adults were dependent on educational attainment, state of health, the available resources and opportunities open to them as

well as cultural norms and traditions. Some of these individuals had limited power to secure rewarding jobs on leaving school, particularly at age 16, that suited their specific situations. Most had made pragmatic choices that had or would enable them to maintain their aspirations (for promotion, for management positions, for long-term careers, for possible future work) within the structural limitations of their lives. Social background, locale and family circumstances all influenced how they viewed employment prospects and the resources they perceived as available to them. Fred, for example, had no qualifications and was unemployed at the point of interview. He had little expectation of securing another job in manual work and having few options and no interest in other types of occupation, he had become resigned to living on incapacity benefits.

*'If they (a potential employer) looked up and saw what CF is all about then sitting in front of a computer, it's no hassle at all but obviously it is for a mechanic or a labourer, they would say, well you're not the right person for the job which is probably true.'* Fred (CF)

Fred saw no particular advantage to being unemployed but equally seeking a job for its own sake held little appeal. Those in the sample who had given up work or who had opted to go part-time had made decisions based on their own (and others) perceptions of their health status and the reality of available alternatives. Structural and cultural factors both supplied these individuals with choices and meanings and constrained them in terms of the options open to them on a daily basis. The thinking and behaviour of these young adults were manifest in and reflective of their social context. Their networks, confined in some cases due to chronic illness, were significant sources of cultural beliefs that had the potential to reduce their aspirations.

The effectiveness of individual agency over structure also may be less instrumental than previously thought. The research undertaken on resilience and self-esteem (Bancroft et al., 2004; Emler, 2001; Schoon and Bynner, 2003) would suggest that individuals who show high levels of competency in the face of adversity do not succeed

to the same extent as young people from more privileged backgrounds. Self-esteem as a concept or form of capital has been found to be intergenerationally transmitted (Emler, 2001). Likewise, resilience appears to be dependent on protective factors such as supportive family networks or access to high bridging capital at a wider level (Schoon & Bynner, 2003). In this study, it appeared that in some circumstances, possessing individual attributes such as competence and aspiration were not sufficient in themselves to guarantee work at a level commensurate with qualifications (see Jackie's quotation on p. 223 above as an example). Health status is likely to be a mediating factor that influences (either adversely or positively) pathways into employment and outcomes over the long-term alongside structural aspects such as social class, ethnicity and gender.

Young people's perspectives change as they mature and encounter new competences, resources and different responsibilities. Within their accounts at interview, some respondents in the study appeared to identify key moments or a particular set of circumstances which had occurred that had caused them to take stock and make changes in their lives. These types of events or experiences exposed the varying degrees of agency and structure in the lives of these young adults and revealed how decisions were made within their specific social contexts. In the study, Vicky's experience of hospital inpatient care and being told that she may require a heart-lung transplant had caused a chain of events that had resulted in her decision to stop work (see p. 181-182 ). Quinn also cited an occasion when he had given up a secure post in the public sector for one within a private company that held more challenge but also more risk (p. 195). Sarah made a decision at age 16 that she would return to education rather than continue in factory work against the expectations of the social mores of her background as well as her teachers at the time (p. 166). These types of moments appeared to signal or result in a shift in perspective on the part of individuals' in terms of their notion of themselves and their envisioning of a future. Others (Thomson et al., 2002; Webster et

al., 2004) have also identified critical points in young people's biographies and explored how these can act as catalysts for change and re-assessment in an individual's life course.

It is important then that young people are not written off as failures at a young age because of chronic illness and/or because they do not attain educational success. Some of these respondents would have benefited from the introduction of a coherent framework of policies (health, educational and employment) at primary and secondary school and beyond to facilitate their transitions to adulthood. Policy incentives and disincentives designed for young people need to take account of their social context and how choices are framed by structural factors over which they may have little control (Jones, 2005). A flexible system to obtain educational qualifications and entry into the labour market would allow those with chronic illness time and opportunity to realise their potential for success at work and in other aspects of life if employment is not a realistic option.

The positive aspects of work also have to be set against the reality of life in the labour market in the current socio-economic climate. Statistics show that employees in Britain work the longest hours in Europe (Roulstone and Barnes, 2005; Taylor, 2002). On top of this, work content has become more pressurised for many employees, as employment is rationalised in ways in which Jarvis and Pratt term 'extensification' and 'overflowing' of work into other aspects of social space (Jarvis and Pratt, 2006). There has also been a dramatic deterioration in workplace satisfaction which appears to be more marked amongst women than men, particularly for those with few educational qualifications (Taylor, 2003). Taylor also provides evidence to undercut the assumption of the dynamic flexibility of today's workplaces (Taylor, 2003). A substantial UK-wide survey in 2000 found that most employees do not enjoy the power to vary their hours of work themselves (Taylor, 2003). These findings taken together suggest that we are moving



towards a more demanding work environment which may restrict rather than increase the opportunities available for those with longstanding illness.

The emphasis placed on paid employment by the UK government through its welfare to work programmes cannot be viewed in isolation from the distribution of capital and power in Britain today and the policies of education, health and the political economy as a whole. Chronic illness presents practical and ideological challenges to employers but the lack of engagement in people management is also a worrying trend. Recent research suggests, for example, that firms put more importance on the quality of leadership among line managers than on any specific human resource initiative (Taylor, 2003). This state of affairs runs counter to the evidence of a positive association between an organisation's performance and its investment in a coherent set of employee policies (Taylor, 2002). As such, the government's 'employment opportunities for all' strategy must engage with a work agenda to enforce anti-discriminatory practice and ensure real choices are available to those with long-term illness including the decision not to work if this is deemed unmanageable. Only then will individuals be willing to disclose medical conditions and make an active contribution to society whatever their class, gender, identity, ethnic origin or health status may be.

## **7.7 Conclusion**

The concept of social capital has helped to provide an explanatory framework from which to explore some of the differences in behaviour and outcome for the respondents in this study. Its value as a theory or set of theories lies in its potential to link individual experience with wider structural processes. The data point to the importance of the interplay between culture, location, social context and agency in the lives of these young adults as they progress through adult years. There is a clear need for a sustained and long-term investigation into the impact of chronic illness on individuals

throughout the life-course in order to understand more fully the effects of health status on pathways into education and employment. Policy intervention needs to recognise the ways in which cumulative and multiple disadvantage may play out through the lives of people with a long-term condition.

The next and final chapter focuses on some of the key health-related findings from the study and their implications for nursing practice and the delivery of health care in Scotland and across the UK more widely.

## CHAPTER 8: HEALTH CARE POLICY AND IMPLICATIONS FOR NURSING PRACTICE

### 8.1 Introduction

The twin areas of chronic illness and work are currently receiving unrivalled attention in UK policy documents throughout health, social welfare and employment-related fields. An ageing population and a falling birth rate have implications not only for the health service but also for the economy as a whole which has witnessed a huge rise in sickness and disability benefit levels since the 1980s (Floyd and Curtis, 2000). Within this context, a fundamental shift in health care is being promoted (HMGovernment, 2006a; SE, 2006d), one that espouses a patient-centred, proactive and flexible ethos alongside a work-focussed agenda that is premised on the goal to promote social inclusion for disadvantaged people in society (DWP, 2003; DWP, 2007; PMSU, 2005). Young adults who are not economically active are also being brought into the policy umbrella under New Deal arrangements and the government drive to improve the educational skills-base of those leaving school (HMTreasury, 2006; SE, 2006b).

This joining up of policy and legislation underlies much of government action and sets out a series of challenges for front-line nursing staff in how they might respond to the needs and demands of service users. The recent requirement, for example, that nurses and Allied Health Professionals (AHPs) 'must undergo transformational change to become enablers' (p. 33) of self-care among individuals signals a radical swing towards health improvement and a much more holistic, public health approach to practice (SE, 2006d). In current UK health care documents, there is also an explicit reminder (HMGovernment, 2006b; SE, 2006d) of the need to improve overall health by making links with other policies and programmes of work being undertaken by local authorities, education, social justice, employment and environment services.

Amid the myriad of policy documents promoting change, the implications which emerge are for health care professionals to develop new modes of thinking, embrace different roles and propose innovative solutions to take forward the health care agenda. This chapter will examine some of the key health-related findings arising from the study in relation to the framework set out by the Scottish health document, *Delivering care, enabling health*, (SE, 2006d) in order to consider the contribution required from nurses and AHP staff to influence, shape and deliver services that meet the needs of the people of Scotland both today and in the future.

## **8.2 Context and culture**

This section places the research study undertaken in context of wider policy and practice issues. It addresses the emphasis placed on chronic illness and employment reflecting the nature of the challenge and the responses needed by health professionals to develop services that cross traditional boundaries including public health, disease management, social care, rehabilitation and research and development. The promotion of a rights-based approach to care advocated in recent Scottish policy documents (SE, 2006a; SE, 2006d) sits well with the established value systems of the caring professions but calls for a more committed partnership approach than that practised hitherto. Within UK policy documents (HMGovernment, 2006a; SE, 2006a; SE, 2006d; SE, 2007), there is also an increasing interest in the concept of 'wellness' and this aspiration is discussed in relation to this study and the various strategies required to promote and improve health among these population groups.

### **8.2.1 Research study in context**

This study was conceived when the UK government was putting in place structures for consumer involvement within the health service (DH, 1999). At that time, health care was being driven by the principles of patient choice and independence backed up by

The Community Care Act of 1990. Enshrined within legislation was the need to involve service users in all aspects of the care they received. Historically, the needs of those with chronic illness and disability have not always been addressed given the emphasis on cure in a health system geared towards acute, secondary care services (SE, 2005; Strauss, 1984).

In order to work in partnership with patients and their families, health professionals need to better understand the individual experience of having a long-term condition and the impact this has on all aspects of day-to-day life. This research project arose out of this rationale but as a nurse working within an acute Hospital Trust, my stance at the start of the study was at least partially informed by a biomedical perspective. The sample of respondents for this study was obtained from hospital outpatient services. In this way, they were perhaps atypical from the majority of those with chronic illness who predominantly interact with health professionals in primary or community care settings. Individuals with cystic fibrosis tend to be managed by specialist centres but those with arthritis and diabetes usually receive formal health care primarily at the GP surgery. It is possible therefore that the respondents who took part in the study had more severe forms of these conditions than if recruitment had taken place using other contacts and sampling strategies.

The focus of the research in the early stages of data collection also changed from that of a mixed methods study whereby information gathered at interview would have supplemented quality of life questionnaires to one which relied solely on respondents' own explanations of their experiences. It became increasingly apparent on meeting and listening to people that managing illness and negotiating the processes of the labour market could not easily be covered by pre-set variables. Also, on reading the disease-specific literature, it emerged that subjective perceptions rather than objective or clinical parameters may be much better at predicting whether people are able to maintain

working lives in spite of long-term illness (Frangolias et al., 2003; Packham and Hall, 2002). Consequently, I changed the emphasis of my approach at interview to concentrate solely on the individual experience of respondents and on the social and employment consequences of differing chronic conditions. Health services have a distinctly clinical bias despite the importance placed on holistic care in the management of chronic disease (SE, 2005). Supporting self-help and enabling strategies will demand substantial changes in practice for nurses if they are to achieve the policy vision of establishing themselves as 'full and legitimate partners' (SE, 2006d) p. 31) in the delivery of health improvement interventions in the future.

### 8.2.2 An evolving model of care

Chronic illness is currently being conceptualised as the main challenge facing the health service at the start of the 21<sup>st</sup> century (DH, 2005; DH, 2006; SE, 2005; SE, 2007b).

Demographic change and the growing numbers of older people with multiple conditions demands a new model of health care as the pattern of disease shifts towards longstanding illness. It is now envisaged that (HMGovernment, 2006a; SE, 2005) instead of a reactive approach with resources concentrated on managing crises within a hospital-based system, more infrastructure needs to be laid down to implement anticipatory, preventative and continuous care.

The Kerr Report (SE, 2005) recommended putting in place a National (Scotland-wide) Framework for Service Change. This model of care emphasised the need for a redesign of services towards local and community-based settings. The transformation needed to achieve whole system improvements, however, necessitates more than a redirection of resources from the secondary to the primary care sector. In 2006, the Scottish Executive provided a policy commitment to move towards developing integrated, collaborative and interdisciplinary partnerships that cross traditional NHS and social care boundaries (SE, 2006d). In particular, community-based networks are being planned

which would offer a wide range of services from assessment, diagnostic testing, treatment to rehabilitation delivered by multi-agency teams (SE, 2006d).

A recent Scottish policy document (SE, 2007) published earlier this year reinforced the need for a more systematic approach to care for people with long-term conditions. Rehabilitation, hitherto a somewhat neglected discipline (Curtis, 2003; Robinson, 1997) has now re-emerged as pivotal to the goal of developing enablement approaches with individuals and carers to ensure best outcomes and value for money. The Scottish Executive (concurrent with similar initiatives being undertaken throughout the UK - see, for example (DH, 2006; DWP, 2004; HMGovernment, 2005) aims to place rehabilitation at the heart of service delivery to 'restore personal autonomy' (p. 14) and equip the public with the skills, knowledge and support to self manage illness where possible and to take greater control over treatment (SE, 2007). Vocational rehabilitation, defined in this document as the process by which people with functional, psychological, developmental, cognitive and emotional impairments can overcome barriers in accessing, maintaining and returning to employment, is declared as integral to this broader rehabilitation model (SE, 2007).

Health improvement initiatives are also being advocated on an unprecedented scale (DH, 2005; SE, 2006d). The language of policy documentation appears to be changing from encouraging NMAHPs (nurses, midwives and allied health professionals) to educate patients (SHEG, 1983; SHHD, 1983) and promote health (DH, 1992) to that of anticipating care, adopting wide ranging public health approaches and supporting 'wellness' (DH, 2005; SE, 2006d). A more exaggerated example of this shift in focus can be found in the UK mental health policy literature (NIMHE, 2005; SE, 2006a) which is explicitly recommending that nurses pursue a recovery agenda with service users in order to promote their well-being and social development. The adoption of the



principles underpinning recovery for mental health services has the potential to extend to professionals supporting people with long-term physical conditions.

### 8.2.3 The concept of 'wellness' in the study

A striking feature in respondent accounts was an emphasis on the normality of living with symptoms of illness. Many others researching chronic disease have reported similar findings (Bluebond-Langner, 1996; Gjengedal et al., 2003; Lowton and Gabe, 2003; Strauss, 1984). A common interpretation is that those who have impairments frequently engage in normalisation strategies in an effort to make light of or deny their condition (Gjengedal et al, 2003; Bluebond-Langner, 1996). An alternative explanation particularly for young adults who experience chronic conditions from childhood might be that symptoms of disease have gradually become an inevitable and unobtrusive part of their biography. In this study, a chronic condition was not necessarily perceived as synonymous with illness. Co-morbidity was common and some respondents had severe forms of disease but mood, timing and context were important factors in determining how symptoms were experienced and managed. As Lowton and Gabe (2003) revealed in their research with individuals with CF, perceptions of health could change according to circumstance but were generally reflective of those of the lay public, that is those who did not have cystic fibrosis. Wellness was dynamic and relative rather than fixed among respondents in this study and included feeling healthy, keeping fit, working and getting on with life in spite of the presence of symptoms and need for medication.

According to Schein, the paradigmatic approach of the health care professional assumes an ideal of a normative state of health and well-being and identifies his or her role as assisting in the recognition and treatment of pathology (whether biological or psychological in nature) and works towards restoring health (Schein, 1987). Clinical theories, mainly derived from medicine, science and psychology provide a ready-made

conceptual framework for assessing patients and their problems and are an important tool for practice. However, they are predominantly based on a model of maladjustment or pathology that may be antithetical to the beliefs and personal meanings given to chronic illness and disability by service users. The role of the qualified nurse is constantly evolving and some have argued that the advent of specialist practitioner status and nurse consultants has eroded the focus on the caring aspects of nursing (Cunningham, 1999; Jinks and Bradley, 2004). Without an understanding of how those with long-term conditions are able to construct meaningful futures for themselves (Jensen and Allen, 1994) and maintain working lives if they so desire, nurses are unlikely to realise their full potential in meeting the rehabilitative requirements of their patients.

Respondents in this study mostly sought to avoid normative assumptions about themselves as 'ill' or 'disabled' viewing these labels as threats to personal autonomy and their capacity to achieve successful lives. Being employed in particular provided an important means of self-definition that signified status and social participation. For most, a diagnosis of a long-term condition was incidental to them as an individual with specific goals and aspirations, and as such, a certain amount of resentment was expressed towards health professionals who were sometimes seen as the main perpetrators of labelling processes. Those with cystic fibrosis, who of all of the groups interviewed were likely to have experienced the most contact with health care staff, felt that the health system itself was imbued with a disease-oriented focus that militated against wider areas of concern. In their contact with health professionals, individuals in the sample were rarely interested solely in the physical or functional consequences of their condition but rather how these might impact on their social worlds including roles in family life and employment and participation in leisure and lifestyle activities. As such, an enabling model of care that works in partnership with patients, carers and

families will need to be grounded in the experiences and perspectives of service users themselves rather than the value-base of any one professional group.

Associated with a broad understanding of what it meant to be well or healthy for the sample was the notion that a chronic condition was but one priority amongst many in day-to-day lives. Most of those interviewed were not incapacitated by their illness and even those with severe forms of disease had periods of relative stability and remission. At these times, managing symptoms was largely automatic and part of the reality of everyday life with energy being spent on work matters, social engagements or other more pressing demands. This lack of prioritisation could on occasions be at odds with the response of health care staff, and the medical profession in particular, who tended to focus on disease management and symptom control divorced from the context of wider social and environmental influences. To work effectively with patients with chronic illness requires not only an understanding of pathology and treatment but a prospective vision and the ability to take into account individual experiences, skills and expectations and how care management can best fit the specific attributes of different service users.

The sample group for this study, comprising young adults with differing levels of disease severity, is likely to represent typical outpatient clientele from the three specialty areas. Their experiences of managing illness and their reported encounters with health professionals suggest that mismatches may occur between what is desired by patients and what is imparted by health care staff. One example of this discrepancy was the types of communication around lifestyle change which emerged as a largely unsolicited element within the interviews. Doctors and nurses were mainly perceived as judgemental and critical in their advice about health improvements rather than respectful and supportive. Some respondents felt particularly vulnerable to suggestions that they had contributed to symptoms of their illness through adopting

unhealthy behaviours such as over-eating, taking insufficient exercise, drinking alcohol, smoking etc. Strategies on how to improve health and well-being had seemingly not been received and, according to interview data, credit had rarely been given when efforts had been made to engage in healthy behaviours.

Corbin and Strauss have argued that illness experience can be conceptualised in terms of three different types of 'work' that must be accomplished by individuals in day-to-day life: illness trajectory work, everyday life work and biographical work (Corbin and Strauss, 1985). This analysis can be helpful in underscoring the challenges faced by people with chronic disease in dealing with the demands of their condition and serves as a reminder that not all will have the energy or see the worth in giving up valued practices. Furthermore, lifestyle activities cannot be separated from individuals' culture, identity, family and social environments and it is unlikely that modifications in these areas will respond to a 'top-down' prescriptive approach (Downie et al., 1990).

The interactive skills of nurses and other health workers may well determine the degree to which complex health improvement activities can be achievable for individuals confronting ongoing health challenges. It seems clear that communication styles that promote and enhance health must become more firmly embedded in clinical practice if health professionals are to succeed in achieving the highest level of wellness amongst patients with chronic illness. Advocating wholesale changes in lifestyle without an empowering framework might be counterproductive and could well damage health care communications. Professional expertise needs to be exercised judiciously in the context of respectful relationships and by validating individuals' knowledge about their unique responses to illness in order to create a climate of trust and partnership. If nurses are to play a prominent role in health improvement activities particularly in the context of chronic illness then they must effect part of the change process themselves in

challenging many of the traditional notions underlying professional practice and in recognising how their interactions currently impact on people in their care.

### **8.3 Capability**

In *Delivering care, enabling health* (SE, 2006d), the mid-section considers the NMAHP contribution needed to develop services that meet the needs of Scotland's population for the 21<sup>st</sup> century. A key objective is for nurses, working in partnership with AHP colleagues, to become enablers and supporters of service users' self-care and self-management abilities. Rehabilitation and enablement constitutes the framework (SE, 2007) within which people with chronic illness gain greater control over their condition and play a central role in identifying their own needs and treatments. Much has been written about promoting self-care among those with long-term health problems and some of this literature will be explored with respect to the study. The research evidence presents rehabilitation as a somewhat underdeveloped area for the nursing profession (Burton, 2000; Nolan and Nolan, 1998; Nolan and Nolan, 1999). There are problems over definitions (Burton, 2000; Nolan and Nolan, 1999; SE, 2007), deficits in knowledge and skills to implement effective rehabilitation interventions (Nolan and Nolan, 1998; SE, 2007) and no universally accepted models for practice (Nolan and Nolan, 1998; SE, 2007; Wade and de Jong, 2000). This section will cover the implications of these issues and suggest what is needed if nurses are to become proactive in leading 'patient-focused pathways' (SE, 2005b) in the care of those with long-term illness.

#### **8.3.1 Self-care interventions and rehabilitation**

Patient education and health promotion are widely recognised as important components of the nurse's role (DH, 2005; Holt and Warne, 2007; SE, 2005b; SE, 2006d) yet the types of rehabilitation activities envisaged by current policy objectives are likely to be unfamiliar territory for many NMAHP staff in practice. The vision set out in *Delivering for Health* (SE, 2006d) depends to a large extent on the delivery of evidence-

based care. NMAHPs are seen as having a significant part to play in generating the research from which effective interventions can be identified (SE, 2006d). Practice development is cited (SE, 2006d) as the vehicle through which research knowledge can be translated into service programmes for those with long-term conditions so that developing NMAHP research capacity is perceived to go hand-in-hand with advancing a patient-led health agenda.

However, there are significant limitations in the current evidence base for self-care interventions. Among these include a lack of comparative effectiveness of different self-care strategies and inadequate evaluation particularly over the long-term (Coulter and Ellins, 2006). It is also unclear whether nurses have the knowledge and/or the skills to support patient-centred activities in a variety of health care settings (Holt and Warne, 2007; Nolan et al., 2001; Robinson and Hill, 1999; Whitehead, 2001).

Bodenheimer et al. make a distinction between patient education and self-management in terms of the outcomes for patients in achieving change. Whereas patient education is seen to focus primarily on providing information and technical skills to enable individuals to follow medical advice; self-management interventions are premised on the goal of empowering people to take active control of their illness and apply problem-solving skills to meet new challenges (Bodenheimer et al., 2002). This difference is believed to be reflected in the methods by which interventions are delivered; patient education being taught through didactic approaches and self-management education through participatory learning techniques.

In their comprehensive review, Coulter and Ellins (2006) found that information delivered as a component of clinical care was by no means sufficient on its own to improve self-care in chronic illness. Others have come to similar conclusions and have explored educational instruction alongside more complex patient-focused interventions including social learning and behavioural modification exercises (Cooper et al., 2001)

coping skills (De Ridder and Schreurs, 2001) and cognitive behavioural therapy (Niedermann et al., 2004). The UK has been particularly active in promoting self-care initiatives principally through the establishment of the Expert Patient Programme launched in England and Wales in 2001 and the Scottish version set up in May 2006, the Long-Term Conditions Alliance Scotland. These initiatives have been based mainly on the chronic disease self-management programme (CDSMP) developed by Lorig and colleagues at the Patient Education Research Center at Stanford University, California. The CDSMP is a generic, lay led, community-based course that is run over six weekly (two and a half hour long) sessions and aims to build patient skills, resources and confidence towards better managing long term conditions (Lorig et al., 1999). Evaluation of this programme has revealed moderate, short-term benefits in health behaviours, levels of self-efficacy and use of health services as well as providing support for those with poorly recognised chronic conditions (Coulter and Ellins, 2006). However, most health professionals were found not to be engaged with or to be directing patients to these courses and many participants felt that they would have derived more benefit from a condition-specific programme (Coulter & Ellins, 2006).

The types and levels of support needed by people who are self managing a chronic illness have been examined by a national telephone survey (Ellins and Coulter, 2005). This study found considerable variation in the UK population in terms of knowledge, confidence and skills for self-management but identified three important general themes that should inform an effective, patient-centred strategy for enabling self-care: good relationships between patients and health care professionals; clear, accessible information and flexibility of service provision to fit with individuals' other commitments (Coulter & Ellins, 2006). In addition to the Expert Patient Programmes, health care teams have themselves developed self-management interventions for specific conditions, usually delivered in hospital settings. These have been particularly evident in the areas of diabetes and arthritis.



The evidence collected by systematic reviews suggests that for people with diabetes, education alone is of limited use to improve blood glucose levels. Psychosocial and educational interventions, however, may lead to a reduction in health service usage for this population group (Hampson, 2001; Steed, 2003). In arthritis, self-management programmes appear to be addressing far broader and multi-dimensional aspects of the disease process for individuals than simply at the level of functional and clinical outcomes. Astin et al. (Astin et al., 2002), Reimsma et al. (Riemsma et al., 2003), and Niederman et al. (Niedermann et al., 2004), for example, found patients improved after being taught cognitive-behavioural techniques and active coping skills although these effects appeared to diminish over the long-term.

Nurses and AHPs are the main professional groups being charged with the management of services to support those with long-term conditions throughout the UK (DH, 2005; SEHD, 2006). Yet the nursing profession has not always realised its potential in meeting the needs of chronically ill populations (Kennedy, 2005; Nolan and Nolan, 1998; Thorne et al., 2000). The effectiveness of a nursing response to support patient self-care interventions is also, at best, somewhat mixed (Kennedy, 2005). In principle, health professionals seem to value patient involvement in treatment programmes but have yet to fully embed rehabilitation or self-care facilitation into everyday clinical practice (Gately et al., 2007). It would appear from the evidence-base gathered so far that self-management programmes cannot be regarded as static, one-stop packages but require ongoing commitment and perhaps the recognition on the part of health care staff that different strategies may be required for different people at different times in their lives.

Nolan and Nolan undertook a comprehensive review of the nursing contribution to rehabilitation and argued that two principal conditions require to be met if rehabilitation practice is to improve (Nolan and Nolan, 1998). These were: that nurses

need a better understanding of the personal meanings that people with long-term conditions attach to their illness, and secondly, that a model of rehabilitation is called for that acknowledges and meaningfully addresses such individual perceptions. Drawing on five different chronic diseases, they outlined a number of areas in which rehabilitation practice might be considered to be deficient in some way (Nolan and Nolan, 1998). The areas of deficit described by Nolan and Nolan (1998) almost a decade ago (an undue emphasis on physical outcomes, failures to adapt generic programmes for individual use, insufficient attention to psychological, spiritual and emotional needs, inadequate consideration of work and vocational aspects, neglect of issues around gender, culture and ethnicity, lack of attention to the needs of carers and failures to address temporal aspects of recovery) would appear to continue today.

Current policy objectives, however, provide an opportunity for nurses to realise their potential with regard to rehabilitation and become proactive in developing patient-centred programmes that provide effective and long-term benefit for those with chronic conditions. The delivery framework advocated in the Scottish Executive rehabilitation document (SE, 2007) is based on the premise that most people with long-term illness and disability would benefit from being seen by a specialist, co-ordinated rehabilitation service (Wade and de Jong, 2000). There are three levels of management envisaged in this framework; self-management for the majority of people, condition management through multi-disciplinary teams targeted at individuals and their carers with less complex needs and case management typically delivered by community or specialist nursing teams for those most at risk of hospital admission.

This framework is constructed around the WHO International Classification of Functioning and whilst acknowledging some social aspects of rehabilitation is essentially biomedical in origin. In particular, there is an explicit lack of emphasis in the model on quality of life issues and a failure to allow for the subjective experiences

of patients (Wade & de Jong, 2000). The Framework document (SE, 2007) does recognise the vocational aspects of rehabilitation but provides little detail in how interagency working will help individuals with long-term illness to remain in or access employment other than by addressing functional impairments. There is a recommendation that NHS Boards and local authorities prioritise rehabilitation services and adopt a whole-systems approach to service delivery.

The preoccupation in the document (SE, 2007) with restoring the functional capacity of those with long-term conditions for work or some other useful occupation, however, effectively ignores the social and environmental constraints faced by these groups of people. In employment, for example, the low work activity rates of disabled populations cannot be explained by levels of disease severity alone. An emphasis on personal adjustment to chronic illness which is perceived to be remedied by way of expert guidance also completely neglects the political context in which health, work and individual choice is played out. In addition, whilst discrimination in the workplace is undoubtedly a serious issue, some young adults with chronic illness may not be well enough to undertake regular paid work (the accounts of Gary, Xanthe and Vicky in this study would seem to support this position). The imperative to do so through employment training schemes, vocational rehabilitation and pressure on benefits may become coercive and this potential must be borne in mind when health care staff are asked to play their part in supporting initiatives for people with long-term conditions. Roulstone and Barnes (2005) claim that new ways of viewing productivity and social worth need to be developed alongside the prospect of working lives. A one-sided agenda in favour of employment runs the risk of further excluding people with disability and ongoing health problems from the mainstream of society.

Health care policy documents represent signposts for future direction of services and practice. They rarely provide a comprehensive review of the evidence-base for change.

The increasing emphasis being placed on self-care and rehabilitation including employment-focused outcomes are likely to present particular challenges to many nurses in practice. Rehabilitation is seen as a process to restore personal autonomy to those aspects of daily life considered most relevant to service users. However, a framework which does not pay due attention to the perceived needs of patients is in danger of providing services that fail to address individual priorities and concerns. In addition, there appears to be scant regard to the structural barriers and health and social inequalities that prevail in society which may undermine any 'therapy-led' rehabilitation programme.

Nearly ten years ago, Nolan & Nolan (1998) described the range of knowledge and skills that nurses needed to acquire in order to fulfil their role in rehabilitation practice. These covered the application of interventions based on pathology of chronic conditions including appropriate use of clinical instruments, understanding of adult learning and counselling concepts, the ability to assess coping styles and use cognitive behavioural processes, assessment of family dynamics, capability to address sexuality issues and to co-ordinate transitions across the healthcare system and other service providers (Nolan & Nolan, 1998). To ensure that these diverse and varied areas are fulfilled is likely to require specialist or advanced role preparation for nursing staff as well as the setting up of multi-professional and multi-agency rehabilitation teams. Focusing on enablement approaches in the NHS will demand a considerable change and orientation in practice. Nurses must be prepared to take forward patient-centred interventions for themselves if the models adopted in secondary, primary and integrated care settings are to adequately address the social context of chronic illness.

## 8.4 Capacity

The final section of *Delivering care, enabling health* (SE, 2006d) centres on workforce issues and the need to ensure that pre-and post-registration courses adequately prepare nurses and AHPs to work across a range of environments, meet a variety of patient needs and take on enabling roles in multidisciplinary teams. There appears to be a recognition in this and previous policy documents (SE, 2005b) that health workers require a better understanding of social inequalities in order to provide anticipatory care, health improvement and self-care enhancement services. The promotion of a values-based model for health care (SE, 2006d) is embraced for all programmes of nursing and this ethos and the caring role of nursing staff are perceived as core to competency-based practice. The recommendation for leadership and the redesign of the nursing workforce required to enable those with long-term chronic conditions meet their needs will be discussed in relation to the research study. Finally, practice-based issues and areas for future research will provide a concluding theme to the thesis.

### 8.4.1 Developing the workforce

*Delivering care, enabling health* (SE, 2006d) makes explicit reference to the various ways in which nurses might contribute to the NHS modernisation agenda to meet changing service requirements. In addition to developing new roles, health staff require education and training to take on patients' self-care and self-management needs. The appraisal of the evidence collected to date would suggest that nurses have some way to go to realise their potential in this regard. In terms of educational preparation, Nolan & Nolan (1999) undertook a review of nursing curricula to determine the extent to which teaching and learning strategies provide the knowledge and skills required to enable the nurse to make a positive contribution to rehabilitation in primary and secondary health care settings. They found that with very few exceptions, rehabilitation, chronic illness and disability did not feature prominently in nursing programmes for basic training or in courses geared towards community health nursing. In contrast, analysis

of the curricula for specialist rehabilitation education revealed that the syllabus appeared top heavy in terms of the content covered. The sheer volume of learning outcomes expected from the student raised questions about the detail in which the various areas of the topic could be addressed. The authors (Nolan & Nolan, 1999) surmised that while inferences had to be drawn from reviewing the curricula in isolation, it was likely that only a superficial appreciation of rehabilitation at best could be achieved.

This research is based on course documentation almost a decade ago and nurse education has presumably changed since that time. A review is currently being carried out by the Nursing and Midwifery Council of the fitness for practice of registrants which is likely to address a number of key issues including clinical competence, practice assessment processes and curricula content of courses. A key message of *Delivering care, enabling health* (SE, 2006d) is that professional education should prepare health workers to meet the agenda set out by current health care policy. It makes clear that some of the assumptions of pre-and post-nurse registration education may need to be questioned in order to ensure that professionals are sufficiently flexible to take on key roles, including caring for those with long-term conditions, within multi-disciplinary and multi-agency teams.

The knowledge base required for effective nursing practice in chronic illness is wide and complex. In terms of the role in rehabilitation, teaching should be driven by an understanding of the social context of chronic illness with the individual and family at the heart of the caring process. There should be an integrated and systematic approach to educational programmes that explicitly sets out social and health inequalities and involve service users as partners in the management of their health. Learning in the workplace needs to complement the values and ethos promoted in the classroom and include a wide variety of service providers. Underlying the educational training is the

need for nurses to develop a fuller understanding of the principles and models that underpin rehabilitation and the differential impact that these may have on service delivery and patients' experience of care.

#### 8.4.2 Leadership

There is an increasing recognition within UK policy documents (DH, 2005; SE, 2005b; SE, 2006d) that nursing is in a state of rapid change. The key to realising the aspiration of developing pathways of care from the patient's point of view (SE, 2005b), we are told, lies in investment in patient/public-focused clinical leadership initiatives. As nurses progress in their career to become co-ordinators of care, they are seen as possessing the potential to become agents of clinical change. The RCN Future Nurse Programme (RCN, 2004) has identified the key attributes of any new nursing role. These include the ability to:

- manage risk and critically evaluate research
- transform organisational and practice cultures
- motivate and influence a range of key stakeholders and teams
- demonstrate transformational leadership
- work across organisational and professional boundaries.

In order to support those with long-term illness, nursing leaders have an opportunity to drive service improvement. A more holistic approach to practice, however, would seem to be required, one that focuses on the whole person in a societal context (including attention to roles in family life, education, work, leisure etc) rather than solely managing symptoms of illness. Delivery of care will also have to be geared towards the individual. If young people growing up with illness such as diabetes, arthritis and cystic fibrosis are to be encouraged to look to the future and make decisions about their long-term health, they must receive developmentally appropriate support that takes into account how this goal fits with other long-term objectives.



Success in negotiating the tasks of adulthood may be based upon and even predicted by the developmental achievements in childhood. This implies that health care professionals working with young people need to offer support not just in relation to attaining disease-specific knowledge and skills but also in terms of the continuing tasks of childhood and adolescence, such as maintaining friendships, building upon academic success and fulfilling valued roles within the family and wider community (Roisman et al., 2004). Effective transition from children's to adult's health services is likely to be important in enabling this process towards independence. There also needs to be a firmer recognition by the government that for some people, even the youngest adults with chronic illness, paid work may not be an attainable goal because of impairments, a lack of appropriate job match to skills or the severity of symptoms experienced.

## **8.5 Areas for further research**

The long-term needs of those with child-onset disease as well as issues associated with work are only now beginning to emerge as a priority for policy and service development in Scotland and the rest of the UK. Some individuals face a complex combination of factors that keep them from finding or sustaining employment including overt and covert discrimination practices. The imperative to work must also be challenged in cases where illness is severe, erratic or particularly burdensome. There is a need for better articulation between the social justice and health care policy agendas to ensure that the economic and attitudinal disadvantages experienced by those with chronic illness are recognised and that steps are taken to ameliorate such issues. In other words, the promotion of paid work as the only route out of social exclusion needs to be addressed in the context of wider deliberation about the values of different forms of contribution to society.

Further research is required to explore the experiences of work and other types of purposeful occupation for those with chronic illness in relation to nature of impairment, age, race, gender, social class and location. A life-course perspective may help to build an understanding of employment as one life event amongst many within a broader social context. Work opportunities are inherently localised in nature and individuals with long-term illness within Britain may well encounter different experiences depending on where they live. The voices of people need to be heard more clearly to inform the development of policy in this area and to improve an awareness of how adults with chronic illness manage to maintain working lives and build successful careers in spite of impairment. Employers appear to require better guidance to deal with employees with health problems so that they adopt positive approaches and provide adequate support in terms of adjustments and flexible working policies. It will also be important to determine the types of resources and assistance required by children with child-onset disorders to maximise their educational experiences, training and employment opportunities as they grow into adulthood and face the labour market as an adult.

## **8.6 Conclusion**

This study sought to explore the factors affecting employment among young adults with child-onset illness. Thirty respondents took part from three different disease groups and from varying socio-economic backgrounds. Their accounts of their experiences provided an opportunity to examine the meanings each held about their health status and how they viewed their work situations and job prospects. Individuals made decisions in relation to their personal circumstances and the opportunities they perceived as available to them. The socio-structural effects of education, family culture and expectations shaped the employment pathways of these respondents and their outcomes at the point of interview. Illness was experienced dynamically and more

acutely amongst those with deteriorating health and five of the sample were no longer in any form of work, training or education.

UK health policy is advocating wholesale changes to the care of those with long-term conditions. There is an expectation that nurses will take on an enabling and supporting role to promote self-management of illness. Employment is conceived of as a means of facilitating a recovery-oriented approach. Health care staff need to be aware of the social context of chronic illness and its impact on individuals and families in order to provide appropriate, holistic and patient-centred care. Only then will services become more responsive and be better placed to provide support for those with long-term conditions in the future.

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## Appendix1



OUR REF: **LREC/2001/8/44**

YOUR REF

PLEASE QUOTE THE ABOVE REFERENCE ON ALL CORRESPONDENCE

Ms Helen Allbutt  
Research Sister  
Respiratory Unit  
Western General Hospital  
Crewe Road, Edinburgh, EH4 2XU

07 December 2001

Dear Ms Allbutt,

**A comparative assessment of employment and health status among young adults with common, child-onset, chronic disease**

Thank you for submitting the amendments or additional information requested by the Sub-Committee for the above protocol. The Chairman of the Medicine/Clinical Oncology II Research Ethics Sub-Committee has now agreed to confirm the Sub-Committee's ethical approval under its delegated authority. An official Certificate of Ethical Review is enclosed together with a list of Sub-Committee members.

Under the terms of the Scottish Office Home and Health Department Guidelines on Local Research Ethics Committees this decision has been notified to the NHS body under the auspices of which the research is intended to take place. It is that NHS body which has the responsibility of deciding whether or not the research should go ahead taking account of the advice of the Research Ethics Sub-Committee and from whom you must obtain management approval before any work on the study can proceed.

Yours sincerely

**Joyce Clearie**  
Administrator  
Medicine/Clinical Oncology II Research Ethics Sub-Committee

cc

LOTHIAN HEALTH BOARD

LOTHIAN RESEARCH ETHICS COMMITTEE

DEACONESS HOUSE

148 PLEASANCE EDINBURGH EH8 9RS

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## Appendix 1

### LOTHIAN RESEARCH ETHICS COMMITTEE

#### CERTIFICATE OF ETHICAL REVIEW

**LREC Reference Number: LREC/2001/8/44**

**Title: A comparative assessment of employment and health status among young adults with common, child-onset, chronic disease**

**Researcher: Ms Helen Allbutt**

The Medicine/Clinical Oncology II Research Ethics Sub-Committee reviewed this proposed study and has agreed that it is ethical and appropriate to be carried out in the Lothian Area. This opinion encompasses all aspects of the application including the Patient/Subject Information Sheet and all other accompanying documentation provided.

The LREC application form, protocol, subject information sheet, information on compensation arrangements, payments to researchers and the provision of expenses to subjects (where appropriate) were reviewed and approved.

The membership of the Medicine/Clinical Oncology II Research Ethics Sub-Committee is shown on the attached sheet.

It is a condition of this opinion that you **must** obtain appropriate management approval from the relevant NHS body under the auspices of which the research is intended to take place **before** starting the study. It is that NHS body which has the responsibility of deciding whether or not the research should go ahead taking account of the advice of the Local Research Ethics Committee. It is also a condition that you are required to notify the Medicine/Clinical Oncology II Research Ethics Sub-Committee **and** the relevant NHS body, in advance, of any significant proposed deviation from the original protocol or application form. Reports to the Sub-Committee and the relevant NHS body are also required once the research is underway if there are any unusual or unexpected results which raise questions about the safety of the research.

Researchers are also required to report on success, or difficulties, in recruiting subjects in order to provide useful feedback on perceptions of the project among patients and volunteers.

Peter Reith  
Secretary  
Lothian Research Ethics Committee

Joyce C Clearie  
Administrator  
Medicine/Clinical Oncology II  
Research Ethics Sub-Committee

07 December 2001

The Medicine/Clinical Oncology II Research Ethics Sub-Committee is fully compliant with the International Committee on Harmonisation/Good Clinical Practice (ICH) Guidelines for the Conduct of Trials Involving the Participation of Human Subjects as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Standing Orders, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997. The Membership List, Standing Orders and Statement of Compliance were included on the computer disk containing the guidelines and application form and are available on request.

# The Lothian University Hospitals NHS Trust



## **WESTERN GENERAL HOSPITAL** **Crewe Road, Edinburgh, EH4 2XU**

21<sup>st</sup> September 2001

Ms H. Allbutt  
Research Sister  
Respiratory Medicine Unit  
Western General Hospital  
Crewe Road  
Edinburgh

Dear Ms Allbutt

**LREC No: 2001/8/44**

**R&D Project ID No: 2001/W/RES/01**

**Title of Research: A comparative assessment of employment and health status among young adults with child onset chronic disease.**

The above project has undergone a review of resource and financial implications by the R&D Office and I am satisfied that all the necessary arrangements have been set in place.

On behalf of the Trust Chief Executive I am happy to give Trust management approval to allow the project to commence, subject to the approval of the appropriate Research Ethics Sub-Committee having also been obtained.

We would ask you to note that under Section 7, question 34, of the LREC Application Form, The Lothian University Hospitals NHS Trust provides indemnity for negligence for NHS and honorary clinical staff wherever research involves patients attending the hospitals. It is not empowered to provide non negligent indemnity for patients or volunteers.

Yours sincerely

**Dr Heather A Cubie**  
**R&D Director**

cc *Secretary, Research Ethics Sub-Committee*



## **RESEARCH & DEVELOPMENT OFFICE**

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**Information Officer:**  
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*RGN, BSc(Hons)*

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*Mrs Glynis Omond*

**Admin Assistant:**  
*Neil Feltham*

## Appendix 2

WESTERN GENERAL HOSPITAL, CREWE ROAD, EDINBURGH EH4 2XU  
Tel: 0131 537 1000

### **PATIENT INFORMATION SHEET**

You are being invited to take part in a research study. Before you decide to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

#### ***Project Title:***

A comparative assessment of employment and health status among young adults with common, childhood-onset, chronic disease.

#### ***Lay Title:***

The impact of health on employment amongst adults with chronic disease.

#### ***What is the purpose of the study?***

This study seeks to find out how young people with chronic disease find work and maintain working lives. We are interested in hearing about your experiences of employment, whether good or bad, and about how working affects your health. We also want to know about your career intentions in the future. Please note that we would still like to talk to you if you are not presently working or if you have never worked at all.

#### ***Why have I been chosen?***

You have been asked to take part because you have a chronic condition that began in childhood. In total, about 30 patients will be invited to take part. Please note that your own employer, if applicable, will not be contacted at any stage by the researcher.

#### ***Do I have to take part?***

It is entirely up to you to decide whether or not to take part. There is no need to do so if you would rather not. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to change your mind and withdraw at any time without having to give a reason. This will not affect the standard of care you receive either now or in the future.

#### ***What will happen to me if I take part?***

If you decide to take part in the study, the researcher will arrange to see you at a place of your choice (either at home, in a research office at the Western General Hospital or in another suitable location). The researcher is a trained nurse who works for the NHS. You will be asked about your experiences of health, schooling, employment and career intentions in the future. This discussion will be recorded on audiotape (with your permission) and will take no longer than an hour. Your name will not be attached to the tape and anything you say will be confidential between the researcher and yourself. You will be asked to fill out 2 short questionnaires which ask about different aspects of your health and about how you are currently feeling. The researcher may also examine your medical notes, with your permission, to ascertain the degree of your illness. The study may take up to five years to complete.

### ***What do I have to do?***

You do not have to do anything or prepare anything before the researcher visits you. If you decide that you would like to take part in the study, you can contact the researcher on the telephone number given at the end of this information sheet.

### ***What are the possible disadvantages of taking part?***

It will be entirely up to you how much information you are prepared to tell the researcher. It is very unlikely that any questions put to you will cause you distress or anxiety. Should you require any further information after the discussion, or wish to discuss anything further, your name will be passed onto a specialist nurse at the Western General Hospital who will contact you. Alternatively, there is an independent advisor to the study, Dr Peter Reid, who is a Consultant Physician at the Western General Hospital, and although not directly involved in the project, he will be happy to give advice.

### ***What are the possible benefits of taking part?***

At present, not much is known about the work experiences of people with chronic illness. In talking about what has happened to you, you will help researchers find out if anything can be done to improve employment prospects for others like yourself.

There will be no direct benefit to you in taking part in the study.

### ***Will my taking part in this study be kept confidential?***

All information collected about you during the course of the research will be kept strictly confidential. A number will be used to identify you. The information will be stored on audiotapes and computer. You will not be identified by name on either of these. Computer access will be restricted to the researcher only and protected by a password.

Your GP and hospital doctors may be informed of your participation in the study. However, they will not be informed about what was said by you to the researcher.

### ***What will happen to the results of the research study?***

The research may be published when all the data are complete and have been analysed. Published reports will not include your name or any other information that may identify you. The audiotapes will be securely stored and destroyed at the end of the research.

### ***Who is organising and funding the research?***

This research study is being organised by a nurse researcher in conjunction with Consultant Physicians based at the Respiratory, Rheumatology and Metabolic Units of the Western General Hospital. The study is being undertaken as part of a PhD degree at The University of Edinburgh. There is no external funding source for this study.

***Who has reviewed the study?***

The study has been reviewed and approved by the Lothian Ethics Committee.

***Contact for further information***

If you have any further questions or you would like to take part in the study, please contact Helen Allbutt, Researcher, SCPME (Tel: 0131 229 8047 or 0131 225 4365).

If you wish to speak to someone not directly involved in the research, please contact Dr. Peter Reid, Western General Hospital (Tel: 0131 537 1768).

**Thank you for reading this information sheet and for considering taking part in the study.**

If you do take part in the study you will be asked to sign a consent form and you will be given a copy of this information sheet and consent form to keep.

**Patient Information Sheet Version 3 (15 January 2002)**

**WESTERN GENERAL HOSPITAL, CREWE ROAD, EDINBURGH EH4 2XU**  
**Tel: 0131 537 1000**

Patient Identification Number for this study:

**CONSENT FORM**

**Title of Project:** A comparative assessment of employment and health status among young adults with common, child-onset, chronic disease.

**Lay Title:** The impact of health on employment amongst adults with chronic disease

Name of Researcher: Helen Allbutt

**Please initial box**

1. I confirm that I have read and understand the information sheet dated 15 January 2002 for the above study and have had the opportunity to ask questions ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that sections of my medical notes may be examined where it is relevant to the research. I give permission to the researcher to have access to my medical notes. ☐

4. I agree to take part in the above study. ☐

Name of Patient	Date	Signature

Researcher	Date	Signature

1 for patient; 1 for researcher; 1 to be kept with hospital notes

## Appendix 3

### CHRONIC ILLNESS AND EMPLOYMENT:

#### INTERVIEW SCHEDULE (BY THE END OF THE STUDY)

**Before interview begins, identify self and provide short resume of study, explain interview procedure, emphasise confidentiality of information, set up audio-tape equipment if consent obtained.**

#### **Education**

I would like to ask some questions about your schooling, about whether or not you liked school, about your school-friends and about whether your illness had any effect on your school-life.

- Can I ask first of all what type of school you went to?

*Probe: State/Private/Special needs*

- Did you go to school in Lothian?

- Did your condition start when you were at school?

- How did you like school?

*Probe: What activities did you do?*

*Did your illness affect what you chose to do or could do at school?*

*Did your friends/teachers know about your illness? How did friends/teachers respond to you? Did you feel differently from others? Were you treated differently?*

- Did you miss a lot of school because of your illness?

*Probe: How much each year?*

- Can I ask what qualifications you obtained at school.

*Probe: Do you feel your qualifications reflect your ability?*

- Did you get any careers advice at school?

*Probe: If yes, nature of it, was it useful?*

- *At what stage did you receive careers advice?*

- When did you start thinking about jobs?

- Did your diagnosis affect the way you thought about the type of job you might do?

- What did you do after leaving school?

*Probe: What age were you?*

- Have you undertaken any higher education?



- **If not**

*Probe: Did you consider a course at University/College?*

*If not, why not?*

- **If yes**

*Probe: Did you mention on your application form that you have a chronic illness*

*(If not, why not)*

*Was it difficult to get a place of your choice?*

*Did you study full-time or part-time?*

*Did you need a lot of time off?*

*How did you find studying?*

*What were the attitudes of friends/tutors?*

## **Health**

- Can you tell me about your health at the moment?
- Are you limited in any way in what you are able to do?
- How do you manage your condition?  
*Probe: Do you need help? What type? From whom?*
- How does this make you feel?
- Do you have support at home? Friends nearby? Self-help organisations?

## **Present Employment**

- Are you working at the moment?
- How long have you worked in this job?
- What is the nature of this work?  
*Probe: Ask about job title, if not clear*
- Do you work part-time or full-time? Any shifts? Whose choice is that?  
*Probe: Would you prefer different hours?*
- Can you remember how you got the job? How did you hear about it?
- Was the job easy to obtain?
- Were you unemployed before getting this job/or were you changing jobs?
- At the time did you mention on your application form that you had a chronic illness?  
*Probe: Why was that?*
- Were you asked about your health or amount of sick leave at interview? if yes, what did you say? Were you open about your illness or not? If you

weren't, have you told anyone about your health problem? Who, and at what stage did you inform them about your condition?

- 17) What are the good things about having a job? What about this job in particular?
- *Probe: financial benefits? Independence? Structure to life? Other?*
- In what ways is having a job important to you?
- Are there any bad things about having a job? Doing this job?
- Do your boss(es) know that you have a chronic condition?
- Do your friends at work know that you have a chronic condition?
- Do you feel that you get treated in the same way as other people at your workplace?

*Probe: If no, in what way are you treated differently?*

- Is there any social life connected to your work?

*Probe Do you take part in that? If not, why not?*

#### **Effect of illness on health and work**

- Do you feel that your illness affects how well you can do your job?  
*Probe: If yes, in what way?*
- Do you worry about the demand of your job on your health?
- Do you worry that your illness might cause you to lose your job?
- Does your diagnosis affect the way you think about what type of job you do?

#### **Sick leave**

- Have you had to take time off work because of illness in the last year?  
*Probe: How much?*
- Was this a good year, a bad year or about average?
- How many times have you had to come to hospital as an outpatient?  
- as an in-patient?
- **If some sick leave:**
- What has been the attitude to the amount of sick leave by your boss, by your work colleagues?
- Do you have to have special treatment whilst you are at work?  
*Probe: If yes, is there privacy for this at work/ Do you try to hide it?*
- Do you take time off when you are ill or do you try to go in at all costs?

### **Previous Employment**

- Have you had other jobs? What were they?
- Have you ever had any difficulty getting a job?  
*Probe if yes, why do you think that was?*
- Do you feel that your illness has ever got in the way of your job or in securing a job?  
*Probe; If yes, why do you think that was?*

### **Benefits**

- Do you still entitled to state benefits because of your illness?
- Do you know how much you can earn and still claim benefit? Is that something that matters to you?  
*Probe: Does that influence whether your choice over part-time of full-time work?*  
*Probe: Do you tell the Benefits Office how many hours you work?*
- Do you feel that your wage or benefits are adequate for your needs?

### **Career/job Aspirations**

- Is there another job you would prefer to be doing?
- Do you look for other types of work/jobs?
- Do you feel your illness prevents you from getting another job/course or from changing jobs easily?
- Do you think about the future at all?  
*Probe: any concerns about your condition? ..about your work or your ability to maintain work?*
- Is there anything else you would like to say which may help this research?
- Is there anything you would like to ask me?